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**SPECIALIZED PALLIATIVE
HOME CARE TEAMS:
COMPLEMENTARY PERSPECTIVES OF
TEAM FUNCTIONS AND INFLUENCES
ON PATIENTS AND FAMILIES**

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**Karolinska
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*This thesis is dedicated to my family, near and far; bringers of light and joy.
Without you I am naught.*

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Specialized palliative home care teams:
complementary perspectives on team functions and influences
on patients and families
THESIS FOR DOCTORAL DEGREE (Ph.D.)

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“She dwelt among the untrodden ways...”

She dwelt among the untrodden ways
Beside the springs of Dove,
A Maid whom there were none to praise,
And very few to love.

A violet by a mossy stone
Half-hidden from the eye!
Fair as a star, when only one
Is shining in the sky.

She lived unknown, and few could know
When Lucy ceased to be;
But she is in her grave, and, oh,
The difference to me!

William Wordsworth

ABSTRACT

Persons with life-threatening illness are increasingly being cared for and dying at home. Palliative care strives to cater to multiple dimensions such as physical, psychosocial and spiritual or existential, and meeting these needs in patients and families requires multiple competencies. Palliative care organizations propose organization and delivery of care in teamwork models; however, teamwork is complex and can be approached from various perspectives. Previous research has identified gaps in palliative care regarding which components of teamwork are most effective.

The overall aim of this thesis was to explore perspectives of team function in specialized palliative care teams, among health care professionals, families and patients. **Study I** entailed translation and cultural adaptation of a research questionnaire. **Study II** entailed qualitative interviews with health care professionals (n=15) working in specialized palliative home care and **Study III** interviews with patients (n=6) and family members (n=7). In **Study IV**, an exploratory design was used. Initially team leaders (n=77) in palliative care reported team function. Next, health care professionals (n=61) reported team development in the group development questionnaire, patients (n=43) reported symptoms in the Edmonton Symptom Assessment System and family members (n=45) reported satisfaction with care in the translated and culturally adapted FAMCARE-2 questionnaire. Results of the studies are: (I) a translated culturally adapted and initially tested Swedish language version of the FAMCARE-2 scale, (II) health care professionals report that competence, communication and organization are crucial components of teamwork in specialized palliative homecare, (III) patients and families report that they experience security and continuity of care due to 24/7 care, sensitivity to changing needs and demonstrating caring, and (IV) specialized palliative home care teams have a core of registered nurses, physicians and social workers. Positive associations were found between team maturity and team effectiveness.

Key words: palliative home care, teamwork, patient, family, health care professional.

LIST OF SCIENTIFIC PAPERS

- I. **Klarare Ljungberg A**, Fossum B, Fürst CJ, Lundh Hagelin C. Translation and cultural adaptation of research instruments – guidelines and challenges: an example in FAMCARE-2 for use in Sweden. *Informatics for Health and Social Care*, 2014, Jan 6: 1-12. E-pub ahead of print.
- II. **Klarare A**, Lundh Hagelin C, Fürst CJ, Fossum B. Team interactions in specialized palliative care teams: a qualitative study. *Journal of Palliative Medicine*, 2013;16(9):1062-9.
- III. **Klarare A**, Rasmussen B, Hansson J, Fürst CJ, Fossum B, Lundh Hagelin C. Experiences of security and continuity of care – patients’ and families’ narratives of palliative home care teams’ work. *Submitted*.
- IV. **Klarare A**, Hansson J, Fossum B, Fürst CJ, Lundh Hagelin C. Team type, team maturity and team effectiveness in specialized palliative home care: an exploratory questionnaire study. *In manuscript*.

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LIST OF ABBREVIATIONS

EAPC	European Association for Palliative care
ESAS-r	Edmonton Symptom Assessment Scale revised
GDQ	Group Development Questionnaire
HCP	Health Care Professional
ICN	International Council for Nurses
SPHC	Specialized Palliative Home Care
WHO	World Health Organization

1 INTRODUCTION

A large portion of my professional life, I've worked as a registered nurse in specialized palliative home care. I loved my job, met many different persons in their homes and spent time with families near death. This meant being in the midst of other persons' lives and deaths, with strong emotions (or not), and love with grieving. Talking in the car, while driving to the next home, often provided breathing room and necessary time for reflection with colleagues. This reflection pertained to what we'd done, what happened and how we felt about it. Sometimes I felt lucky to be working nights, since due to the merged districts during night shifts, we had longer driving times and thus what seemed like more time to debrief. As a nurse, I was in the home alone, representing a team, but rarely with the actual team. Contact between us, working in the specialized palliative home care unit, mainly happened in the office or by telephone. For me, that raised questions about teamwork. Even though many services offer 24/7 care, maybe teamwork was not intended for health care professionals working off-hours, evenings or nights? I also wondered to myself if there can be teamwork with different persons working different shifts, when the actual team is formed from one shift to another. That is one starting point for this thesis.

The overall aim of this thesis was to explore team function within specialized palliative home care, including perspectives from patients, families and health care professionals. It is my hope that this thesis can contribute to improve care for persons with life threatening illness and their families. Furthermore to inspire health care professionals to reflect on clinical practice and to consider their personal investment and responsibility in teamwork.

2 BACKGROUND

The summary chapter of this thesis describes the palliative care context with regard to care recipients and care providers, theory regarding teams and teamwork in health care settings, and quality indicators for palliative care. The focus is on aspects of teamwork within specialized palliative home care (SPHC) as a way to organize and provide care to meet the diverse needs of patients and their families.

In Sweden, approximately 89 000 persons died in 2014.¹ In this group, the second cause of death was solid tumors. Place of death has shifted from two-thirds of total deaths occurring in hospitals and one-third outside hospitals to approximately fifty-fifty.² Palliative care in Europe has been assessed and the care offered in Sweden is considered 'advanced integrated', with specialized palliative home care (SPHC) teams in operation since the 1970's.³ In the National Palliative care Registry of palliative care teams, presently 140 health care services in Sweden report that they offer palliative care,⁴ however, regarding place of death, only around 10 percent of persons in Sweden die in specialized palliative care.⁵ Looking at organization of care, teamwork is the recommended model for health care professionals within specialized palliative care, both internationally and nationally.⁶⁻⁸ Worldwide much information and research regarding teams and teamwork is available, within SPHC teams however, confirming evidence and research is needed.⁹ How patients and families perceive care by a team is warrants further exploration and furthermore, evidence regarding how standards and guidelines are interpreted and executed by different care providers is scarce. Working as a team seems present in many providers' mission statements, while how teams actually work together in practice is unclear.

2.1 THE PALLIATIVE CARE CONTEXT

The palliative care framework has been fundamental to this thesis project and has infused the approach, the design and the execution of research.^{7, 10} More specifically, the chosen ontological position entails acknowledging and carefully considering implications of the inherent complexity in human beings with multiple dimensions, such as physical, psychological, social and spiritual/existential. Aspects of dignity and respect have been considered in the research process, striving for a collaborative relationship amongst members of the research group as well as with participants in the studies. The term health care professionals (HCPs) is chosen as an inclusive term, striving to

emphasize teamwork rather than adhering to and upholding undisputed values of individual health care professions.

2.1.1 The palliative care framework

Palliative care aims to relieve suffering and promote well-being for persons living with life-threatening illness.⁷ It is known as active care that claims to neither hasten nor postpone death and where death is regarded as a normal process.⁶ Historically, Dame Cicely Saunders initiated palliative care in modern times with her groundbreaking work at St Joseph's Hospice in London, which was a starting point for the hospice movement;¹⁰ later operationalized in her work as medical director in St Christopher's Hospice. Current definitions of palliative care build on this early work and continue to emphasize quality of life, symptom management and embracing different dimensions (physical, psychological, social and spiritual/existential) as a desired standard.^{6, 7, 11} The scope of care is suggested to encompass the patient, the family and the community.⁶ In these definitions, teamwork is stated as the desired standard for the organization of palliative care. Wording in the definitions varies from "trained multi-professional team"⁷ to "is interdisciplinary in its approach"¹¹ and "uses a team approach".⁶ Interestingly, the extent to which the definitions explain the terminology and the meanings of teamwork varies.

A palliative care approach entails interacting with persons who face life-threatening illness on their terms and planning for care together, depending on the wishes of the person.¹⁰ Dignity is often mentioned as a guiding beacon for palliative care, along with autonomy, justice and respect.

2.1.2 Total pain and multiple dimensions in a person

In 1959, Dame Cicely Saunders¹⁰ discussed whether a patient should be informed that he/she is dying or not. She wrote that the guiding principles should be love, as in compassion and understanding, and making an informed decision depending on the situation. She emphasized that this is rarely easy and continued:

"Physicians and nurses who have heart and time to listen will have all types of problems, mental, moral and spiritual, brought to them... We have a responsibility to do the best we can for the people who turn to us, for it may be that someone who has been helping the patient with his physical needs has the key to his confidence and the first opening to help him in this way" (p.15).

These words come from some of the first publications guiding care of the dying. The concept of ‘total pain’ was first introduced in 1964.¹⁰ In addressing pain, mental distress and social as well as spiritual problems are said to be equally important and therefore also need to be managed. This was a novel concept that emphasized the multiple dimensions in a person and the intricate connections between what had previously been regarded as a solely physical phenomenon. Eventually holistic care was introduced and the inclusion of the need to consider the multiple dimensions in a person became a standard in palliative care, thus introducing and requiring a mix of health care professionals to meet these needs.

2.1.3 Persons receiving palliative care

Persons receiving palliative care usually have a diagnosis with implications that threaten their survival.¹² These persons may be children or adults with a variety of diagnoses, although cancer is still a common diagnosis in specialized palliative care settings.¹³ Death is uninvited, yet has become a reality sooner than initially anticipated. Living day-to-day with an existential threat presents challenges.¹² For example, Fincham et al.¹⁴ reported that patients with advanced cancer feel alone with their cancer. Receiving a diagnosis separated patients from others and evoked feelings of loneliness. Sand and Strang¹² reason that existential loneliness is closely associated with death and makes talking about and discussing death even more challenging. Death is ever present and yet life around continues as usual. Axelsson et al.¹⁵ found that, for persons receiving hemodialysis and approaching death, the deteriorating body becomes a constant reminder that death is near. Thoughts of death fluctuate and existential issues are intertwined with physical, social and psychological dimensions. Similar results have been reported from cancer patients in home care by Melin-Johansson et al.¹⁶ Living in a distressed body puts a stop to activities and was described as living with a death sentence that controlled everything, and a consequence of this was isolation and loneliness. These findings point to death as being ever present, in various ways, in these persons’ (patients) lives.

The main needs, as reported by patients and informal caregivers in McIlfratrick’s¹⁷ study, include social support and provision of practical care, respite care, psychological support, and information and choice. The value of a comprehensive approach to assessing palliative care needs is emphasized. Breaking palliative care needs down further, symptom management is considered to be one of the top priorities according to the WHO⁷ and Cicely Saunders¹⁰. Cancer patients in palliative care report a high

prevalence of symptoms, as described by Molassiotis et al.¹⁸ in 2006. The most commonly reported symptoms were lack of energy, dry mouth, feeling drowsy, problems with sleep, pain, loss of concentration, cough, nausea, shortness of breath and feeling irritable. This is confirmed in a more recent 2013 study by Oechsle et al.¹⁹, where lack of energy, tiredness and pain were commonly reported as daily occurrences. In this group, 98 percent of patients reported at least one physical or psychological problem occurring frequently or constantly within 24 hours of admission to a palliative care ward. The median number of symptoms was five. In summary, with regard to physical symptoms, persons receiving palliative care are often troubled by multiple simultaneous symptoms, and require support and assistance with symptom assessment, management and evaluation. Alongside the physical symptoms, these persons are most likely to be in an existential flux and struggling to come to terms with the changed conditions of existence.

An increasing number of persons with life-threatening illness chose to be cared for and to die at home according to a review by Gomes et al.²⁰ and Higginson et al.'²¹ paper from a plenary session in the European Association for Palliative care conference. In many countries, patient preferences are not met and the majority of patients do not die at home.²⁰ Factors such as socioeconomic background, and cultural or ethnic background seem to be influential. There is also a regional variation in the number of persons with cancer who are likely to die at home.

Studies from the past 15 years in Northern Europe investigating patients' and families' experiences of palliative home care have reported that experiencing a sense of security²²⁻³², accessibility of 24/7 care,^{22, 24, 25, 28, 29, 31-33} being able to remain at home^{22, 24-26, 29, 31, 32} and experiencing continuity of care^{23-25, 31} are key components in the work of the SPHC teams. In 2012, Milberg et al.³¹ outlined an overview, a theoretical model, of dying patients' and family members' experiencing palliative home care as a 'secure base'. A sense of security is created for example through trust in the HCPs, being recognized as an individual, experiencing burden relief, being informed and through everyday life at home.

2.1.4 Families in palliative care

Families of persons facing life-threatening illness are sometimes called family caregivers, next-of-kin or family members. In this project, family or family member is used for spouses, partners, family members and friends, who may or may not be

involved in caregiving activities, but who are close to the patient. Often family members are family caregivers, however, they might not refer to themselves that way. ‘Family’ and ‘family member’ are words that are chosen to embrace a wider, more inclusive stance. However, when referring to previous research that uses the ‘family caregiver’ terminology, it is reported using the terminology chosen by those authors.

Family caregivers’ reasoning regarding provision of palliative care at home has been explored by Wennman-Larsen and Tishelman in 2002²⁹ (using the family caregiver concept). The families reported that other options for care were not available and therefore care at home seemed to be the only available choice. The other main reason for providing care at home was fulfilling the wishes of the sick family member. A more recent study of bereaved families by Borland et al.³⁴ in 2014 describes the duality of a stressful situation, being exhausted, and with life fundamentally changed, while the commitment to caring for a loved one was a source of inspiration and dedication. A review of family caregiving within palliative care outlines three major reasons why family caregivers need to be offered support, described as follows by Hudson and Payne.³⁵ Firstly family caregivers have unmet needs and problems such as increased morbidity, financial disadvantage, social isolation, and yet they are still responsible for tasks such as symptom management. Secondly, family caregivers lack experience of caring for dying persons and are often excluded from care planning. Finally, family caregivers have a potential for producing positive outcomes such as improved care, increased well-being of the patient and, on a national level, their contributions save money for health care services.

In a study comparing reports of symptom burden by patients and family caregivers, families tended to overestimate patients’ symptom burden.¹⁹ It is suggested that these results reflect emotional distress in the families. Family caregivers have been reported to need social support and the provision of practical care, together with psychological support and information¹⁷ and, in addition, Stajduhar et al.³⁶ stress that families need to learn how to provide palliative care at home. Meanwhile, findings of depression, strain, fatigue and total mood disturbance in family caregivers have been reported³⁷ since families of persons receiving palliative care live in demanding and existentially exhausting circumstances. Determining how to best meet the needs of families is therefore imperative.^{35 37} Support of families would benefit from a comprehensive approach taken locally (team level) and at governmental, health authority and research council levels³⁵.

2.1.5 Organization of health care as clinical microsystems

The organization of health care can be seen from the viewpoint of a person seeking and receiving care, that is as a clinical microsystem.³⁸ This is a patient-centric view of health care systems. In this perspective, a person has a health need and goes to see a health care provider. As soon as the person has met HCPs and exchanged information, a clinical microsystem is formed. The system has inputs, processes, outputs and feedback loops. These clinical microsystems are the building blocks of a health care system. There are three domains that are important for a system to work well.³⁸ Firstly, the will to provide better care and service, secondly a constant flow of ideas on how care and services can be improved, and thirdly the ability to execute tests and change plans to operate a smooth and effective health care service.

Functioning microsystems are dependent on the intelligent use of data, gaining detailed knowledge of the patients served, the quality of connections to other microsystems and on engaging everyone in the microsystem to do the work and to keep improving the work.³⁸ Ideally, persons moving through the health care system, and various microsystems, should be able to make the journey along a seamless tapestry.

Clinical microsystems are part of a larger system with different provider units.³⁸ Patients are placed at the center, surrounded by a microsystem, which in turn is surrounded by a mesosystem and finally a macrosystem that encompasses all systems. The mesosystem could be clinical programs or centers and the macrosystem could be a hospital or integrated health system. All these systems operate and interact in the provision of health care. In a patient-centered model for organizing health care, patients should be able to report that they receive the care they want, when they want it and how they want it.³⁹ This is at the core of clinical microsystems and patient centeredness. SPHC teams may be considered as microsystems in themselves, involving persons facing life-threatening illness and their families.

Delivery of health care occurs in highly complex environments, relying on multiple teams of HCPs,⁴⁰ or microsystems³⁸ as described earlier. For SPHC teams, care is provided in persons' homes. Even though different clinics work separately, coordination is necessary, both for patient safety⁴⁰, to optimize care and to use resources wisely. In our fast-paced societies with technical advances, organizations will continue to change.

2.1.6 Health care professionals in palliative care teams

Specialized palliative care teams often include physicians, nurses, social workers, physiotherapists, occupational therapists and nutrition specialists.^{41, 42} Physicians and nurses are often constants, while other professions may act as consultants and provide input when needed or requested.¹¹ The expectations are that these different professions will contribute to the delivery of palliative care, bringing expertise from respective areas (medical, nursing, social work etc.) together and thus integrating competencies with the end result being ‘good’ quality care provided by a team. However, achieving multidimensionality in teamwork is not guaranteed by merely merging different professions into a team.⁴³

Lindqvist et al.,⁴⁴ reporting caregiving activities in the last days of life, conclude that fundamental human needs near the end of life are complex and sophisticated. Patients and nurses report that psychological aspects, such as interpersonal communication, are more important than physical aspects⁴⁵ and the caregiving activities described by Lindqvist et al.⁴⁴ pertain to multiple dimensions. This is confirmed by other studies, for example Axelsson et al.¹⁵ on thoughts of death and dying when living with hemodialysis, and Fincham et al.¹⁴ who studied cancer patients’ experiences of supportive care. In both studies, patients emphasize the importance of having a relationship with a HCP and being able to turn to them regarding sensitive issues.

2.1.7 Core competencies for professionals in palliative care

The European Association for Palliative care has issued a consensus paper on competencies for clinical practice that are relevant, irrespective of profession, and that may be used for guidance within palliative care in a European context.⁴⁶ The core competencies are intended as a tool for joint standards and vocabulary for palliative care providers throughout Europe. Applying palliative care in the setting where patients and families are based is the first competency. The second is to enhance physical comfort throughout the disease trajectory and the third, fourth and fifth deal with meeting the psychosocial, social and spiritual needs of patients. The sixth competency is responding to families’ needs and the seventh is responding to the challenges of clinical and ethical decision-making in palliative care. The eighth is to practice comprehensive care co-ordination and interdisciplinary teamwork, while the ninth is to develop interpersonal and communication skills appropriate to palliative care. The tenth and final competency is to practice self-awareness and to undergo continuing professional development.

Health care professionals offering a palliative care approach or general palliative care, should possess these core competencies.⁴⁶ Specialist palliative care has further competency demands, which are not addressed in the EAPC consensus paper. For HCPs who frequently work in palliative care, but with their main clinical focus elsewhere, general palliative care is recommended. HCPs with their main designation in palliative care need specialized knowledge, skills and competencies to work with complex problems. Education for specialist palliative care is commonly offered at higher education institutions and universities.

Clearly, working in the palliative care context is complex. It involves persons facing life-threatening illness (with all connotations associated with death), in relationships with family members (facing possible bereavement), while being cared for at home by HCPs, in interlinking organizations (microsystems), with multiple professions. Added to that, HCPs are charged with providing dignified, high quality palliative care through teamwork; which in turn demands certain levels of competence in various arenas.

2.2 TEAMS AND TEAMWORK

2.2.1 Groups of persons and teams

Traditional definitions of teams often include characteristics of being two or more persons working interdependently towards a shared goal and making a concerted effort to reach that goal.^{40, 47, 48} Health care teams often fluctuate depending on time and day, with HCPs working in shifts and part-time.⁴⁹ Some definitions state that two persons cannot be a group or a team,⁵⁰ others emphasize that groups of persons are not necessarily teams, often referring to cohesion, and that combining persons into a group does not automatically generate a team.⁴³ A pragmatic way of defining a team is by considering how the persons involved view themselves and how they are seen by others, that is as a separate entity within a larger organization.⁴⁸ In health care, teams involve mixing different professions which adds to the complexity.⁴⁹

2.2.2 Definitions of teamwork

Teamwork has been defined and described in different ways, and using different words. One example is interdisciplinary collaboration which has been defined as an interpersonal process that leads to achieving goals that could not have been achieved by a single team member.⁵¹ The rationale for organizing health care through working in a team structure is the ability to achieve results that are possible because of the interaction

between two persons, where the outcome becomes more than what one person could accomplish. The assumption is that teams will improve health care delivery and produce better outcomes through enhanced clinical expertise by the joint efforts of individual HCPs.⁵² Bronstein⁵³ identified components of interdisciplinary collaboration: *interdependence, newly created professional activities, flexibility, collective ownership of goals and reflection on progress*. *Interdependence* refers to team members needing each other in order to perform health care activities. *Newly created professional activities* refers to collaborative acts that accomplish more than independent acts and *flexibility* entails deliberate role-blurring, depending on needs. All team members share the responsibility for success through the *collective ownership of goals*, while *reflection on progress* means setting aside time to talk about work. Organized reflection about work and structures for collaboration are necessary to improve outcomes.

A concept analysis of teamwork concludes that teamwork in health care is:

“...a dynamic process, including two or more health professionals with complementary backgrounds and skills, sharing common health goals and exercising concerted physical and mental effort in assessing, planning or evaluating patient care. This is accomplished through interdependent collaboration, open communication and shared decision-making. This in turn generates value-added patient, organizational and staff outcomes.”

(Xyrichis & Ream, 2008, p.238)

Dynamics, sharing common goals and making an effort are pointed out as key components in teamwork. This distinguishes teams from groups, where groups need to inform each other but work tasks are not interdependent.⁵⁴ Groups can be suitable in a task-focused environment, while teams have shared goals that necessitate working together and, moreover, place demands on interpersonal relations. Health care teams face difficulties in achieving effective teamwork^{48, 49, 55} and research is warranted to understand the components of teamwork, for example when, in what circumstances and how does teamwork contribute to better patient outcomes.^{52, 56}

2.2.3 Team development and team functioning

Teams and teamwork can be explored further by studying team development. Studies of persons placed in a group to work together and going through different developmental phases as a group, have been described by Susan Wheelan.^{57, 58} In brief, the phases are described as follows. *Dependency and inclusion* is characterized by dependency on the group leader. This phase is also called *Forming*.⁵⁹ Members of the group aim to identify

acceptable behavior and act accordingly. Group members tentatively and politely explore boundaries. The second phase, *Counterdependency and fight*, or *Storming*, is characterized by conflict and flight from task.^{58, 59} Issues of power, authority and competition are debated. This phase has the potential for creating stability in the group, if the phase is successfully negotiated. It is a way of delineating common ground, values, goals and norms for future work. If groups remain stuck in phase two, frustration, conflict and feelings of confinement will significantly hamper group performance. This may be described as internal processes interfering with the assignments.⁶⁰ The third phase, *Trust and structure* or *Norming*, is characterized by attention to structures and roles that increase the groups' ability to work effectively.^{58, 59} Planning is also a large part of phase three. If the conflict phase has been adequately managed, the group will feel more secure, and trust more in each other and in the leader. These prerequisites allow a more mature group to proceed with the actual work. In the fourth phase, *Work or Performing*, the group is characterized by an increase in task orientation and open exchange of feedback. Working in a group requires freedom to express ideas and information.^{58, 60} If a group member feels inhibited, the chances are that the group is stuck in an earlier stage. Awareness of time is another characteristic of phase four groups since work occurs in a fixed time frame.

The degree that team members and their work are integrated provides a perspective on teamwork. This has been described among others by Thylefors and Persson,⁶¹ in three themes of team functioning: multiprofessional, interprofessional and transprofessional. The characteristics of each type of team functioning are described in Table 1.

Table 1. Themes of team functioning as adopted from Thylefors et al, 2005.

Function	Multiprofessional	Interprofessional	Transprofessional
Role specialization	Team roles are specialized and everyone concentrates on own tasks.	Roles are specialized but everyone is expected to interact.	Although roles are specialized, everyone must also be prepared not only to complement, but to replace each other when necessary.
Task interdependence	Tasks are usually performed in a determined sequence.	Tasks are partly interdependent and must be coordinated.	Team members as well as their tasks are interdependent.
Coordination	Coordination is based on supervision or standardization.	Everyone has to coordinate their activities.	Coordination is achieved by direct close interaction, flexibility and improvisation.

Task specialization	Tasks are specialized and only those with a special professional education are allowed to perform the task.	Everyone must be prepared to adjust to the task.	Everyone must be prepared to adjust to the strengths and weaknesses of the others.
Leadership	The team leader functions as a traditional manager.	The team leader functions as a 'coach'.	The team leadership varies with the situation; the team is self-regulated.
Role interdependence	'Do your job the best way you know.'	'Do your job and cooperate.'	'Do your job in an interactive way and be ready for continuous adjustments.'

The description indicates that the different ways of functioning place different demands and expectations of performance and interaction on team members. The target areas of role specialization, task interdependence, coordination, task specialization, leadership and role interdependence are all described depending on levels of collaboration and integration necessary to complete team task. In multiprofessional teams, each HCP does his/her job in a determined sequence, supervised by a traditional manager. The individual HCP has no need to coordinate activities with others in the team. This may be contrasted to interprofessional teams where tasks are interdependent and require coordination. One person cannot perform tasks without interacting with other team members. The leader in an interprofessional team functions more like a coach. In transprofessional teams, individual HCPs must be able to replace each other as needed, and all must be prepared to adjust to the strengths and weaknesses of team member. In these teams, leadership varies with the situations and the team may be considered self-governing. In a fast-paced health care context, with HCPs weaving in and out of the team,⁴⁹ this may be challenging. Whether a team is required, or if a group is sufficient,⁵⁴ certainly can be questioned and discussed further.

Lack of time has been identified by Thylefors⁶² as a barrier to teamwork, though her conclusion is that time is important and may be used as an excuse not to collaborate. Wheelan⁵⁸ suggests that resources to perform work are imperative and that groups must be able to use available resources that are necessary for the task. Not all time is devoted to work per se; a significant portion of time is devoted to group maintenance such as dealing with interpersonal issues that arise. Cohesive groups with good social relations tend to be most effective,⁴⁰ perhaps in part due to the team taking time to reflect on processes.⁵³ It has been argued that the best teams are the ones that fluctuate between

group and team, pending need and without instruction.⁵⁴ A collective way of thinking, feeling and acting has been empirically identified in expert teams,⁴⁸ which possibly could explain the ability to shift from a team approach to a group approach without instruction.

Several models have been developed to conceptualize and explain team performance and effectiveness.⁶³ In general, team performance measurement is a systematic process for quantifying aspects of team functioning; aiming to capture teamwork and task work processes.⁴⁸ Assessment of teams often refers to a summary statement of competence within the team, while evaluation is associated with a process of identifying strengths and weaknesses that can be used to develop the team. For example, Burke et al.⁶⁴ provide an advanced input-throughput-output model that comprises twelve core variables representing individual and team level, including the postulated resulting cognitive and attitudinal states. Adaptation is essential in ever-changing organizations and teamwork is identified as a mechanism by which organizations enhance their capacity to adapt. Lemieux-Charles and McGuire⁴⁷ suggest the use of multiple models tailored to particular team types and work processes rather than single models of team effectiveness in organizational studies. Informed by Cohen and Bailey's⁶⁵ model of team effectiveness, Lemieux-Charles and McGuire⁴⁷ provide the Integrated (Health Care) Team Effectiveness Model (ITEM) representing a broad map of the dimensions of teams that are central to address in health care research, see Figure 1. This model emphasizes task design and the organizational context in which a team operates (e.g. guidelines, autonomy, diversity), team processes (e.g. communication, decision-making, cohesion) and team effectiveness (e.g. outcomes, satisfaction, quality).

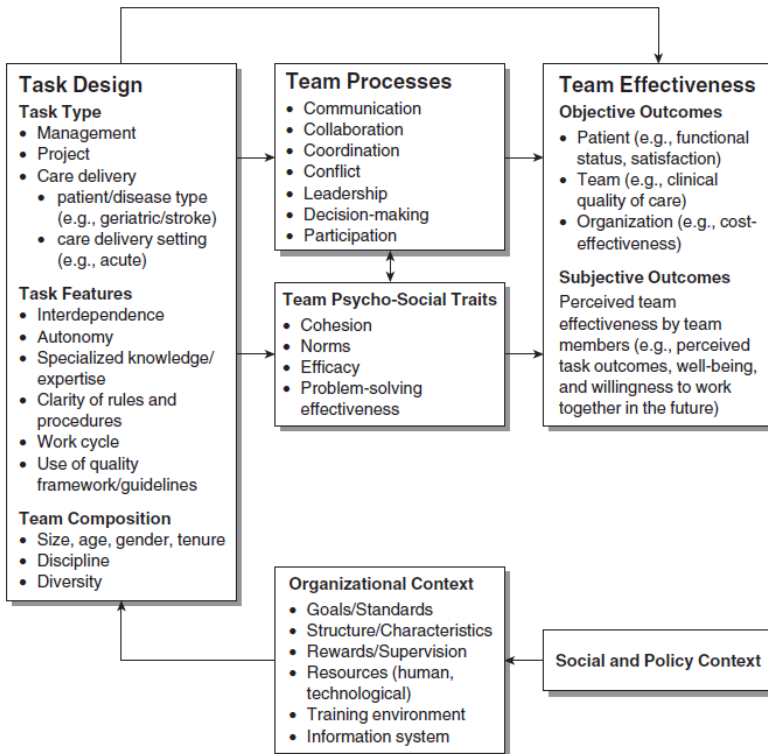


Figure 1. Integrated (Health Care) Team Effectiveness Model (ITEM) as outlined by Lemieux-Charles and McGuire.⁴⁷

Finally, the ITEM model suggests that team effectiveness can be measured by outcomes such as patient satisfaction, quality of care and effectiveness as perceived by stakeholders.

In conclusion, definitions of teamwork and how teamwork can be operationalized has been approached by numerous researchers. The ITEM model provides a comprehensive map of important dimensions of teamwork to guide researchers and as such, has become a beacon in this project.

2.2.4 Team membership and team leadership

Membership in a team implies responsibility and duty. From the concept analysis and definition of teamwork by Xyrichis and Ream⁵⁵, one may conclude that a health professional must have a profession, skill and make an effort in providing care. Depending on how the team functions (multi-, inter- or transprofessionally), then

membership entails different expectations with responsibilities and duties accordingly.⁶¹ Collaboration, communication and shared decision-making are other demands placed on team members. If developmental perspectives are added, then team members may be responsible for assisting the group to move forward by clarifying roles and establishing norms for collaboration, as described by Wheelan.⁶⁶ Irrespective of which perspective one chooses, being a member of a team is a complex phenomenon in itself.

Investigating typologies of teams in health care settings, Andreatta⁴⁹ found four types, sorted as ‘stable’ or ‘variable’ in the areas of team personnel and team roles. The findings indicated that most of the 25 teams studied were stable with regard to team roles and variable with regard to personnel. In health care organizations with high turnover and HCPs working in shifts, perhaps this is to be expected. In Andreatta’s study, all stable-stable teams were found in ambulatory settings and the variable-variable teams were found in critical care or urgent care areas.

Baker, Day and Salas suggest that team performance relies on individuals in teams having the prerequisite knowledge, skills and attitudes to make teamwork possible,⁴⁰ if they do not, teamwork will not happen. Acknowledging that teams are built on individuals is an important factor in team functioning. The necessary knowledge, skills and attitudes they outline are found in Table 2.

Table 2. Knowledge, skills and attitudes necessary for teamwork described by Baker et al.⁴⁰.

Team leadership	Direct and coordinate team; assess and develop team; motivate, plan and organize team; establish positive atmosphere.
Mutual performance monitoring	Develop common understanding of team environment and apply appropriate strategies.
Back-up behavior	Ability to anticipate team members’ needs through accurate knowledge of responsibilities. Ability to shift workload to achieve balance during periods of high workload.
Adaptability	Ability to adjust strategies based on environment; reallocation of intra-team resources; altering course of action in response to changing conditions.
Shared mental models	An organizing knowledge structure of team tasks and how team members will interact.

Communication	Exchange between sender and receiver irrespective of medium.
Team/collective orientation	Belief in importance of team goals over individual goals. Taking others' behavior into account during group interaction.
Mutual trust	The shared belief that team members will perform their roles and protect the interests of their team mates.

As well as team members, each team has one or more leaders. Several models of leadership in health care are available^{60, 67} and different circumstances may warrant different kinds of leadership. Presently, health care organizations and health care providers are expected to increase productivity at a reduced cost. Transactional leadership with reinforcement and punishment has been a common model in health care settings, but it is dated and not aligned with altruistic principles.^{67, 68} Transformational leadership aims to motivate persons to look beyond their own interests and to perform above expectations to promote team or organizational interests, as opposed to personal interests. Servant leadership strives to reach higher, through serving others in an effort to help them reach their goal. This new model is suggested for the current circumstances in the health care sector. Servant leadership works with self-awareness, self-knowledge and self-reflection, in order to develop leadership and enable leaders to understand their purpose, their beliefs and individual characteristics. Ethical and moral aspects of servant leadership require leaders to put the physical, emotional and financial needs of patients first.

Situational leadership theory is a team-oriented theory that assumes that the leader of a group wants to develop the group.⁶⁰ The general idea is for the leader to adapt to the needs of the group either by directing, coaching, supporting or delegating. This theory takes into account that both the group and the leader develops. This is in line with the leadership knowledge, skills and attitudes described by Baker et al.⁴⁰ where the leader directs and coordinates, assesses and develops, motivates, plans and organizes the team. These assignments and skills can be used by the leader as a tool box, depending on current circumstances and needs. In order for team leaders to traditionally manage a team, or coach, or allow self-regulation,⁶¹ and utilize the 'correct' tools or input

depending on the team development phase,⁵⁸ talking about process, reflecting and evaluating teamwork surfaces as not only desirable but crucial for the whole team.^{48, 53}

2.3 QUALITY INDICATORS IN PALLIATIVE CARE

2.3.1 Measuring quality of care

SPHC teams in palliative care often have the WHO definition as a guiding ideal. In the definition, palliative care is stated as an *'approach that improves quality of life,'*⁷ and this implies and suggests standards for care. 'Good' or high quality palliative care is an elusive goal and so measuring quality of care through various aspects has been argued to be necessary⁶⁹ in order to guide quality improvement strategies and goals of care. There have been several initiatives to establish quality indicators for palliative care⁷⁰⁻⁷³, however, many quality indicators for palliative care have not been evaluated and therefore associations between quality indicators and outcomes of care remain unclear. Payne, Leget, Peruselli and Radbruch⁷¹ suggest that a current challenge is to propose globally relevant quality indicators, i.e. indicators that are valid irrespective of access to resources. Furthermore, a 2013 review⁷⁴ concluded that most indicators were concerned with process or outcome of care, while only a few addressed structure. One example from 2014 of proposed quality indicators for a European context found ten validated domains and 52 quality indicators,⁷² see Table 3.

Table 3. Validated quality indicators for organization of palliative care in Europe.

Domain	Number of valid indicators	Examples
<i>Definitions of palliative care</i>	2	Comprehensive care emphasized.
<i>Access to palliative care</i>	16	Availability of palliative care 24/7 throughout disease trajectory.
<i>Infrastructure</i>	7	Single-bed rooms, facilities for relatives, specialist equipment.
<i>Assessment tools</i>	1	Need for validated instrument to assess pain and other symptoms.
<i>Personnel in palliative care services</i>	8	Introductory training continued training and weekly meetings.

<i>Documentation of clinical data</i>	14	Structured medical records with information about physical, psychosocial, social, spiritual and cultural aspects.
<i>Quality and safety</i>	1	Documentation of targets for quality improvement.
<i>Reporting clinical activity</i>	1	Record of clinical activities.
<i>Research in palliative care</i>	0	No useful indicators found.
<i>Education in palliative care</i>	1	Standardized learning objectives for basic and continued training as well as specialized training.

In this European example, the quality indicators in the domain regarding personnel state that good cooperation is important in the multiprofessional team.⁷² Further, that a multiprofessional team must consist of at least a physician and a nurse while a social worker, a psychologist and a physiotherapist are stated as “essential”. All team members should have training in palliative care and, furthermore, there should be weekly meetings, with all professions reviewing referrals and care plans. These ideal quality indicators are suggestions or recommendations of areas to prioritize when addressing palliative care quality. However, individual countries, governments and health care agencies assess needs and resources, interpret recommendations and construct their own agendas. In a national perspective, a Swedish review of policy documents concludes that there is a lack of clinically relevant quality indicators for palliative care in existing national guidelines.⁷⁵ Lind et al. continue by emphasizing that developing general and specific quality indicators is important in order to gain tools to increase quality of care, while including patient and organizational perspectives.

Outlining essentials for improving quality in cancer care (including palliative care) in the United States, Berry and Mate⁷⁶ highlight the following six areas: 1. Team-based care (to avoid fragmentation and to improve treatment in complex situations), 2. Concurrent palliative care and curative treatment (disease, symptoms and stressors are managed well), 3. Prepare family members for caregiving (avoid social isolation, mental fatigue, depression), 4. Facilitate continuous connection (reduce vulnerability,

dependency and powerlessness), 5. Broaden the geographic reach of clinical excellence and 6. Adopt payment-system reforms. These are in line with European quality indicators, though constructed based on interviews with patients, families and HCPs as well as visits to health care services within the cancer care spectrum.

2.3.2 Questionnaires, measuring outcomes of care and research challenges in palliative care

The measurement of outcomes of care is imperative for the evaluation of care and quality improvement.⁷⁷ Using questionnaires to measure outcomes of care highlights the importance of ensuring that a questionnaire measures the intended variable in complex health care organizations and services. A multitude of questionnaires have been developed internationally and, in order to make comparisons across countries and languages borders, Hudson et al.⁷⁸ suggest that translating and using existing, well validated questionnaires is better than creating new ones. This is in line with recommendations^{79, 80} where using validated, reliable scales may reduce the risk of inappropriate or unethical conduct in health care practice and research.

High quality research in palliative care has some inherent challenges.⁸¹ Patients in palliative care are seriously ill and their condition will deteriorate until they die; this presents a challenge since attrition rates may be due to death.⁸² In one study of end-stage cancer patients, half of the participants died before data collection could be completed.⁸³ Another study regarding symptom burden in patients summarized that having access to longitudinal data and a larger sample would strengthen the results.¹⁹ Chen et al.⁸² conclude that research in palliative care is seriously hampered by the challenges, and research is needed to overcome the barriers.

Researchers have attempted to gather evidence through systematic reviews of research regarding outcomes of care within specialized palliative care.^{56, 84, 85} In 1998, Hearn and Higginson⁸⁵ stated that the few RCTs and observational studies available give ample evidence that conventional care is inadequate, and that specialist palliative care improves symptom management and increases satisfaction of care. Ten years later, in 2008, Zimmerman et al.⁸⁴ stated that there is little evidence to support the view that specialized palliative care teams are effective for dying persons with regards to quality of life, patient and caregiver satisfaction and economic costs. However, in an up-dated review in 2010, Higginson and Evans⁵⁶ concluded that studies indicated positive benefits for specialized palliative care. The areas where positive benefits were identified

were pain and symptom management, hospital admissions and improved satisfaction for patients and caregivers. These disparate results may be indicative of the challenges in studying outcomes of care for dying persons in palliative care. In their summary of lessons learned in 25 years of palliative care research, Bruera and Hui⁸⁶ emphasize that research must be conducted independently of funding since research into the most important questions may not be funded and may, in fact, be conducted by groups with no budget or resources. This is in line with Chen et al.⁸² results in a study of barriers to high-quality research in palliative care, where lack of funding was the first barrier. The other barriers were institutional capacity, the lack of competence in the researcher workforce, the challenging nature of the population and, finally, public and professional discomfort with palliative care. Aoun and Nekolaichuk⁸⁷ similarly identify challenges of conducting palliative care research concluding that ‘outside the box’ strategies are necessary in order to improve the evidence base. They suggest that a new system for classifying research is needed since most studies in palliative care are at a lower level of evidence than RCTs and systematic reviews.

2.4 PROJECT RATIONALE

Teamwork is a desired standard in specialized palliative care and is emphasized by leading organizations.^{6, 7, 11} Palliative care teams have been described as complex, adaptive, dynamic systems that exist in context and change over time,⁸⁸ and ambiguity regarding teamwork may lead to local-level interpretations.⁸⁹ Organizations in health care are complex, consisting of a series of microsystems, connecting to each other in mesosystems and macrosystems³⁸ and SPHC teams may be considered to be independent microsystems. Outcome indicators and outcome assessments act as an invaluable source for evaluating care and interventions,⁷⁷ like patients' and families' satisfaction with care. Developing new instruments might not be the wisest choice⁷⁸ since there is an abundance of reliable instruments which makes the translation into new languages and cross-cultural adaptation of instruments as highly relevant.⁹⁰ Persons facing life-threatening illness and impending death may experience physical, psychosocial, social and spiritual/existential distress.¹⁷ Patients and families in palliative care are facing the challenges of probable emotional distress, learning how to care for a dying person and solving practical problems, while at the same time dealing with bereavement processes^{17, 36} and families in palliative care often also have serious unmet needs and challenges.³⁵

The inherent complexity of health care organizations, teamwork models, persons with life-threatening illness and their families provide the back-drop for this project. There are knowledge gaps concerning how the organization of care in the home setting affects care delivery and outcomes for patients and families and HCPs are expected to respond to patients' and families' needs through work in teamwork models, while providing care in the homes of patients. More consolidating research is needed into patients' and families' experiences of SPHC teams in order to better serve with high quality palliative care, catering for the diverse dimensions of persons, and upholding dignity, respect and autonomy.

3 AIMS

3.1 GENERAL AIM

The general aim of this thesis was to explore perspectives of team function in specialized palliative care teams, among health care professionals, families and patients, in order to gain a deeper knowledge of structures and relationships so as to optimize team functioning.

3.2 SPECIFIC AIMS

3.2.1 Study I

The aim was to translate and culturally adapt the FAMCARE-2 scale for use in Sweden.

3.2.2 Study II

The aim was to explore team interaction among the members of specialized palliative care teams.

3.2.3 Study III

The aim was to investigate manifestations of teamwork in narratives of care episodes by patients and families in specialized palliative home care.

3.2.4 Study IV

The aim was to identify team types in specialist palliative home care in Sweden, and also to explore associations between team type, team maturity, and team effectiveness in SPHC teams.

4 METHODS

4.1 OVERVIEW OF THE STUDIES

The investigation of teamwork through the experiences of persons in health care has been central to the studies in this thesis. Both qualitative and quantitative methods were used in order to allow complementing perspectives, provide richness and give room for nuances. An overview of the studies is found in Table 4.

Table 4: Overview of the studies.

	Study I	Study II	Study III	Study IV
Aim	To translate and culturally adapt the FAMCARE-2 scale for use in Sweden	To explore team interaction among the members of specialized palliative care teams	To investigate how the teams' work is manifested in care episodes narrated by patients and families receiving specialized palliative home care	To identify team types in specialist palliative home care (SPHC) in Sweden, and also to explore associations between team type, team maturity, and team effectiveness in specialized palliative home care teams
Design and methods	Translation and validation of instrument, qualitative approach	Descriptive, qualitative interviewing	Descriptive, qualitative, critical incident interviewing	Exploratory quantitative study, questionnaires
Participants	6 forward translators (P, N, R) 3 backward translators (N) 6 experts (senior researchers; P, N, O, S) 2 family members 5 clinical experts (P, N, S, O)	15 health care professionals (P, N, H, O, S)	5 patients 6 family members 6 clinical or research experts (N)	61 HCP (P, N, H, O, S) 43 patients 45 family members

Data collection	Multiple translations Expert review	Interviews	Interviews	Questionnaires
Data analysis	Forward-backward translation Decentering technique	Content analysis	Critical incident technique Thematic qualitative analysis	Descriptive statistics.

P = physician, N = nurse, S = social worker, O = occupational therapist, H = physiotherapist, R = researcher, HCP = health care professional

4.2 PHILOSOPHY OF SCIENCE AND EPISTEMOLOGY

The value and use of philosophy as stated by Russell in 1912⁹¹ holds that philosophy, unlike mathematics or physics, cannot present any ‘truths’ useful to humankind. The value of philosophy lies in its uncertainty. For a person to go through life without philosophy means being held captive by prejudices and common sense in the context one exists in, and totally without the involvement of reasoning. For this person, the world remains explainable, determined and obvious. If philosophy is introduced, existence becomes more complex and all things, common and unusual, may be questioned. Russell claims that freedom can be found in philosophy and that philosophy should be studied because through this our intellects become enriched and our minds become greater with the challenge.

The distinguishing features of science can be determined by looking at the methods that scientists use to investigate the world.⁹² Dahlberg, Dahlberg and Nyström⁹³ maintain that ontology, epistemology and methodology are considered to be the main concepts in the philosophy of science within health and caring research. Ontology is the science of being or the nature of existence dealing with, for example, questions such as “what is existence?”. In this project, we have endeavored to explore and investigate participants’ experiences of providing care or being receivers of care, that is to say a social constructivists perspective focusing on meaning-making for individuals affected by culture.⁹⁴ All statements about existence depend on the worldview. Research therefore aims to capture the *‘diverse understandings and multiple realities of persons’*. These are conducive to the rich descriptions that are strived for in qualitative research⁹⁵ and in a quantitative approach are given room through the use of individual questionnaires. Epistemology describes the theory of knowledge; what is evidence and what is knowledge? This is closely linked to the ontology of social constructivism and can be

understood accordingly; a universal explanation is not pursued, rather the capture of diverse understandings and several realities is strived for.⁹⁴ The use of established methods in the research process allows inferences to be made about knowledge, or evidence, based on the research results.⁹ Methodology is concerned with the scientific method and how we describe, for example, existence. The use of qualitative research methods is in line with a diversity of understandings, allowing different ways of viewing reality and individuals' experiences. Quantitative methods may complement the picture by providing information based on a broader scope.⁹ Guided by the research questions, a combination of qualitative and quantitative methods was used in this thesis, aiming for greater validity and increased integrity of the results⁹⁶ through a more comprehensive view comprising several perspectives of teamwork in SPHC. In qualitative research, knowledge is constructed based on human experiences⁹⁷ and this research approach encourages interpersonal relationships during data collection.⁹⁴ I believe that as well as turning to HCPs for their experiences of providing SPHC in a team structure, it is necessary to include patients' and families' experiences of teams' work in SPHC in order to make inferences about the organization of care and present a more complete picture. At the same time, the use of quantitative approaches allows statistical generalization⁹ and greater scope for conclusions as well as guidance for clinical practice. These two ways of approaching research complement each other and together generate a knowledge base on which to build health care practice.

The concepts of objectivity, validity and generalization have been important throughout this research project. Objectivity means that for research findings to constitute evidence they have to be more than what a researcher believes or wishes. Validity means that the results did not occur by chance but are based on a systematic approach. Generalization means that the results have relevance to persons not involved in the study⁹³ and have clinical applications. The studies in this project have been conducted with attention to normal research practice, carefully adhering to systematic, established methods and with meticulous documentation in the name of transparency. Priority has also been given to allowing time for reflection and questioning the results, and questioning possible inferences.

4.3 ETHICAL CONSIDERATIONS

The studies were conducted in accordance with the World Medical Association's (WMA) Declaration of Helsinki, Ethical principles for medical research involving human subjects⁹⁸ and the International Council for Nurses (ICN) Code of Ethics for

Nurses.⁹⁹ The principles in the Helsinki declaration were amended in 2013 but, since this project started in 2010, the 2008 amendment has been our guide. The WMA guidelines stipulate that the lives, health, dignity, integrity, right to self-determination, privacy and confidentiality of research participants must be protected. The ICN specifies similar values described from a nurses' point of view. The four fundamental responsibilities for nurses are promoting health, preventing illness, restoring health and alleviating suffering.⁹⁹ The preamble emphasizes respect for human rights, and the rights to life, choice, dignity and to be treated with respect. Nursing care is respectful of age, color, creed, culture, disability and illness, gender, sexual orientation, nationality, politics, race and social status. The guidelines, attitudes and approaches from both policy statements have been considered and followed throughout the project.

Conducting research in palliative care can mean working with a vulnerable population. Patients in palliative care may be experiencing physical, psychological, social and spiritual or existential distress.⁸¹ Concerns about research involving this group have been expressed since they are a captive audience, often highly dependent on their carers and experiencing a range of symptoms. Vulnerability, reduced capacity and limited life expectancy are concerns regarding research involving this group. However, the indications are that even very ill persons may want to participate in research for altruistic reasons, and derive satisfaction from doing so. It is recommended that, for research in palliative care, considerable care and effort must be taken so that the highest possible ethical standards are adhered to and, furthermore, that there is no reason to consider all patients and families in palliative care as vulnerable and requiring special protection.⁸¹ Researchers must prove that their research questions are important and that the findings are generalizable.

The studies in this thesis were approved by the Regional Ethical Review Committee, Karolinska Institutet, Stockholm, Sweden (dnr 2010/1490-31/3). The participants were informed both verbally and in writing for studies II and III. Participants in study IV received written information and also contact information for the research group, in case they wanted verbal information or further clarification. Participants gave verbal consent for participation in interviews (II, III) and completed questionnaires as an indication of consent in the questionnaire part (IV). Permission to withdraw at any time without question or repercussion was emphasized verbally in all interviews.

4.4 STUDY I

4.4.1 Participants

In study I, the participants comprised nine translators, six palliative care research experts, two family members and five clinical experts. The forward translators (n=6) were all native Swedish speakers working in health care, three with palliative care experience (physician, RNs) and three (physician, RN, researcher) from other fields. Three of the forward translators were men and three were women. The back-translators (n=3) were native English speakers working in health care in Sweden (RNs) and all were women. All of the senior research experts (n=6) had at least ten years experience of palliative care research (physician, RNs, social worker, occupational therapist); four were women and two were men. The family members, both women, participating in the cognitive interviews had, at that time, a family member admitted to SPHC. The clinical experts (n=5) had at least ten years' experience of working in palliative care (physicians, nurse, social worker, occupational therapist).

4.4.2 Design, procedures and analyses

The measurement of outcomes of care from the perspectives of families is important in order to be able to provide adequate support.³⁵ FAMCARE-2 was identified as being suitable for this project since evidence indicates that it is a reliable scale for measuring family caregivers' satisfaction with care, in persons with advanced cancer.^{100, 101} The translation, cultural adaptation and initial testing was performed using inspiration from a qualitative research approach, which here comprises systematic reflection,⁹⁴ negotiated consensus¹⁰² and a decentering stance.¹⁰³ The ongoing, systematic reflection pertained to own voice and perspective (preconceptions) in balance with staying true to research process values of objectivity and generalizability. This occurred both at an individual level and within the entire research group.

Translation is not an optimal word since the process requires going beyond literal translation in order to capture the connotations of the original wording¹⁰⁴ and so requires multiple approaches. For example semantic equivalence (the meaning is the same after translation) can be present without conceptual equivalence (the same theoretical concept is measured) and vice versa.¹⁰⁵ Other important dimensions for cross-cultural equivalence, as outlined by Flaherty et al., are content equivalence (is relevant to the culture), technical equivalence (the method of assessment is comparable) and criterion

equivalence (the interpretation of measurement result is the same as the norm in the culture).

4.4.2.1 *The FAMCARE-2 scale*

The FAMCARE-2 scale¹⁰⁰ consists of 17 items where family caregivers rate their degree of satisfaction with services provided by the health care team, see Appendix 1. The items address areas such as patient comfort, information about treatment, attention to symptoms, team availability and emotional support. The clarification of which aspects are important to patients and families may help health professionals improve carer support and satisfaction.

Since this questionnaire was created in the English language and had not been translated to Swedish, translation and cultural adaptation were necessary. Brislin's classic steps for cross-cultural research¹⁰³ and Guillemin, Bombardier and Beaton's recommendations¹⁰⁶ were used in determining the steps and process for this study. Brislin's model has been adapted to increase efficiency and to strengthen the integrity of the process,¹⁰⁷ for example by adding a team of independent bilingual translators to perform independent, simultaneous translations. The independent translations are then discussed among the translators and, if there are serious discrepancies, the process of translation and back-translation is repeated until agreement is reached.

The procedure used in this translation project is illustrated in Figure 2. The dotted lines in the figure indicate that cultural adaptation was not explicitly discussed during translations, however culture is ever present¹⁰⁸ and it is probable that the persons performing the translations were influenced.

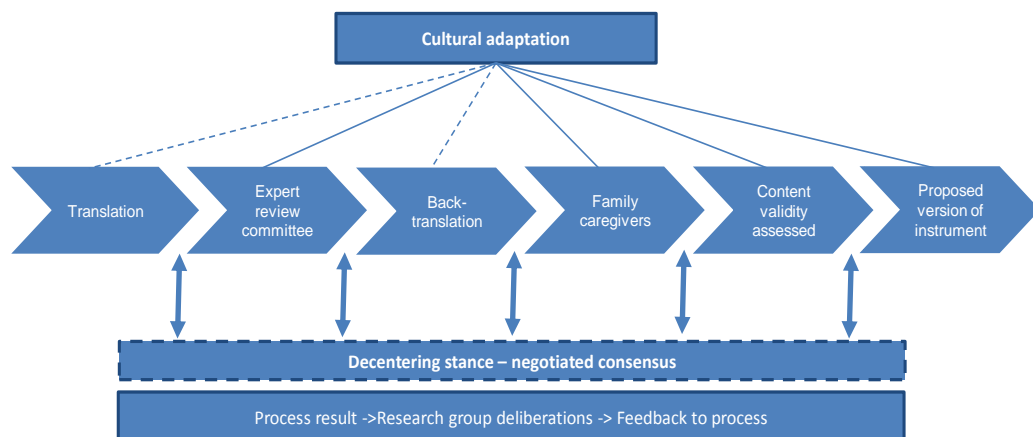


Figure 2: The process of cultural adaptation, decentering stance and negotiated consensus in the translation process. The research group deliberations took place after each step. Dotted lines to cultural adaptation indicate that cultural issues were not explicitly discussed in these steps.

4.4.2.2 *The decentering stance*

The decentering stance was introduced by Brislin¹⁰³ in 1970. Decentering means that the researchers use alternate perspectives, where both languages are considered equal and the original wording may also be challenged. The focus is on the underlying meanings of words, sentences and concepts. The purpose is to enable space for reflection and the shifting of perspectives with regards to wording.

4.4.2.3 *The five steps used in the translation and cultural adaptation process*

Step 1 – Forward translation

The initial translations from English to Swedish were performed by three groups. All persons had Swedish as their first language, but were proficient in the English language. Each group translated and discussed their translations before submitting them to the research group. This was done to strengthen the process and increase efficiency while minimizing regional language variations.¹⁰⁷

Step 2 – Expert review and cultural adaptation

A bilingual expert committee gathered to assess the translated instrument, to compare it to the original, and to assess clinical credibility with regards to clarity and

completeness.⁷⁹ These discussions resulted in a proposed first version of the questionnaire in the Swedish language.

Group discussions were held in the research group at this point and after each of the following steps.¹⁰²

Step 3 – Back-translation

Back-translations of the proposed Swedish version were performed by three nurses with English as their first language. They were all clinically active nurses, working in palliative care and general care.

The submitted translations were reviewed and discussed in the research group. They did not find any discrepancies in the translations; the merits of using the back-translation method were therefore discussed. The proposed version of the questionnaire from the expert group was amended slightly with regards to grammar and correct language use (verb tense), and a proposed Swedish version was then ready for further testing.

Step 4 – Family caregiver input, cognitive interviews

Two family members caring for persons with life-limiting illness were interviewed. A ‘think aloud’ method was used which entailed the person reading the items in the questionnaire and completing the questionnaire while commenting on wording, content or any other pertinent issues.^{109, 110} This was done to get an initial assessment of face validity. Cognitive interviewing has successfully been used to improve the content validity and reliability of instruments through assessing relevance and clarity via the intended population.¹¹⁰

Step 5 – Content validity

The content validity of the proposed, translated version was assessed by health professionals with extensive clinical experience (minimum 10 years) who were identified as clinical experts in the target area of FAMCARE 2, specialized palliative home-care. Calculation of the average proportion of item-level content validity index (CVI) was used to assess overall scale-level CVI¹¹¹. The participating health professionals were asked to rate each item on the translated scale from 1-4, keeping the relevance to family caregivers in mind. For each item on the scale, the proportion of expert ratings that were relevant (3) and highly relevant (4) was then calculated. This resulted in a numerical unit per item, I-CVI. All the I-CVIs were then summed and the

sum was divided by the number of items. This average is the scale-level CVI (S-CVI). A CVI score of .80 or better indicates a good content validity, however when calculating average scale-level CVI .90 is recommended.¹¹¹

4.5 STUDIES II AND III

4.5.1 Participants

In study II, fifteen health care professionals were interviewed, eleven women and four men, ranging in age from 30 to 70 years. Ten had worked in palliative care for nine years or more, three for more than thirty years. The five with the shortest experience had all worked in palliative care for between five and nine years. Their professions comprised five registered nurses, five physicians, two physiotherapists, one occupational therapist, one social worker and one assistant nurse. Nine of the participants worked in urban areas, three in suburban areas and three in rural areas, see Table 5.

Table 5. Characteristics of participants in study II.

Characteristics	Number of participants (n=15)
Age	
<i>30-40</i>	<i>1</i>
<i>41-50</i>	<i>5</i>
<i>51-60</i>	<i>6</i>
<i>61-70</i>	<i>3</i>
Gender	
<i>Women</i>	<i>11</i>
<i>Men</i>	<i>4</i>
Profession	
<i>Registered nurse</i>	<i>5</i>
<i>Physician</i>	<i>5</i>
<i>Physiotherapist</i>	<i>2</i>
<i>Occupational therapist</i>	<i>3</i>
<i>Social worker</i>	<i>1</i>
<i>Assistant nurse</i>	<i>1</i>
Years in palliative care	
<i>5-8</i>	<i>5</i>
<i>9-14</i>	<i>5</i>
<i>15-20</i>	<i>2</i>
<i>>30</i>	<i>3</i>
Location	
<i>Urban area</i>	<i>9</i>
<i>Suburban area</i>	<i>3</i>
<i>Rural area</i>	<i>3</i>

In study III, thirteen participants were interviewed, comprising eight women and five men ranging in age from 50 to 89 years. Six patients (three women, three men) with advanced, malignant diagnoses were interviewed, as were seven co-habiting partners (five women, two men). These included six patient/family member dyads who were interviewed separately. Participants were recruited through palliative care services in five geographic locations in Sweden, including urban, suburban and rural settings.

In striving to gather rich data relevant to our aim,⁹⁴ the focus was on persons sharing experiences of teamwork in SPHC. The initial idea regarding sample size was to have 15-20 participants; however, during the course of data collection the sample size was regarded as emergent and flexible. Fifteen HCPs and thirteen patients and families were interviewed, and this was deemed sufficient to fulfil our aim. In organizations and for persons and families near death, time and resources are valuable. This was also taken into account to minimize the burdening of patients and families.

4.5.2 Design and procedures

The design of studies II and III was qualitative, with interviews being the method used for data collection. Denzin and Lincoln¹¹² offer a definition of qualitative research as “*a situated activity that locates the observer in the world. It consists of a set of interpretative, material practices that make the world visible*”. According to this definition, qualitative research reveals pre-existing ‘facts’. Malterud⁹⁵ refers to qualitative research as a “*systematic and reflective process for development of knowledge that can be somehow contested and shared, implying transferability beyond the study setting*” meaning that here knowledge is developed in a process.

Sandelowski⁹⁷ however succinctly presents qualitative research as “*a diverse collection of approaches to inquiry intended to generate knowledge actually grounded in human experience*”, perhaps allowing a wider scope for generating knowledge, while focusing on the foundation for knowledge that is firmly grounded in human experience. Some researchers in palliative care state that qualitative methods imply that researchers are active in the creation of data and in its analysis,⁸¹ thus aligning themselves with a constructionist perspective. Constructionism deals with making meaning on a collective level, influenced by society and culture,⁹⁴ and further holds that it is impossible to separate experiences from the influence of culture. The researcher is then interactive with the data and the analyses.⁸¹ In study II, descriptively exploring team interactions through qualitative interviews set out to reveal knowledge that already existed. In study

III, the approach was more that of creating knowledge together during the process of qualitative interviewing and reflection on experiences.

Study II had a general qualitative design with a descriptive, naturalistic approach striving to describe aspects of team interactions in terms of the meaning that the participants gave them,¹¹² with results and themes emerging inductively. Study III was inspired by Critical Incident Technique (CIT)¹¹³ and thematic content analysis,¹¹⁴ assuming a constructionist perspective investigating manifestations of teamwork in patients' and families' narratives of care episodes involving the work of SPHC teams.

Critical Incident Technique (CIT) was developed by Flanagan in 1954 aiming to gather facts about behaviour in particular situations in order to solve practical problems and develop psychological principles.¹¹³ Today this method is described as being firmly lodged in a qualitative paradigm.^{115, 116} The focus is on critical events (which promote or detract from an activity) and data collection is often through interviews. Data analysis requires a frame of reference and either inductively forming categories emerging from the data or deductively sorting them into a framework. For study III, the critical event was care by a SPHC team (care episodes) and the palliative care framework was an acknowledged preconception in the analyses.⁹⁵

4.5.2.1 Inclusion criteria

In order to include HCPs (physicians, RNs, OTs, PTs, SWs, ANs) from urban and rural areas, as well as different team sizes, purposive sampling was used with the aim of selecting rich cases to study⁹⁴ which would shed light on the team interactions in question. In our case, purposive sampling comprised the use of a group characteristics sample in combination with quota sampling, so that the proportions of HCPs in SPHC teams were considered. The sample was divided into three equal sized groups: physicians, RNs and other HCPs. The inclusion criteria were: current employment in a specialized palliative care team and a profession as specified above.

The inclusion criteria for patients and family members were: currently admitted to care in a specialized palliative home care team or caring for a person admitted to specialized palliative home care. The exclusion criterion was persons under the age 18 years.

4.5.2.2 *Data collection*

Data for studies II and III was collected through qualitative interviews. Participants were recruited via team leaders of SPHC teams, which is a common way of recruiting in Sweden. Swedish laws of confidentiality and integrity prohibiting the sharing of patient lists and similar information were adhered to, thereby protecting both patients and families. In order to introduce some measure of randomness, team leaders were asked to approach HCPs on duty the next day, or patients and/or families due to receive visits from the SPHC team the next day. In both studies interviews were conducted in a place convenient for the participants. For the health care professionals, this was at their place of employment, i.e. a conference room or an office. For patients and family members, this was in their homes and individual interviews were conducted in kitchens, living rooms and bedrooms.

4.5.2.3 *Interview approach*

For the HCPs, the interview guide consisted of circles, in mind-map fashion, on a piece of paper. When meeting health professionals, the conversation would often start automatically based on the information letter and, in order to maintain the flow, the interviewer picked up on where the participant started and eventually ensured that all ‘circles’ on the interview guide were covered. See interview guide in Appendix 3 (in Swedish).

In the interviews with patients and family members, critical incident technique was used.¹¹³ This meant that the interview guide contained questions regarding health care situations asking for examples of care episodes. True to CIT, questions were formed trying to establish a sequence of events, i.e. the order in which occurrences took place.¹¹⁵ Critical incidents in this study were defined as situations described by participants where care by the team was demonstrated. See interview guide in Appendix 4 and 5 (in Swedish and English).

4.5.3 **Analyses**

The interviews were audio recorded, with permission from individual participants, and transcribed verbatim by secretarial assistants. For both studies, analysis started when all the interviews were completed. The transcribed texts were listened to, interview by interview, while the text was proof-read for accuracy. Discrepancies were discovered in some texts and corrected so that the text represented the exact words spoken in the

interviews. Pauses were identified with dots (...). Other exclamations such as coughing, crying or changes in tone of voice were not included in the analyses, and therefore not included in the transcribed texts.

4.5.3.1 Content Analysis

Content analysis has been extensively used and interpreted in different ways.¹¹⁷ Krippendorff¹¹⁸ describes it as an exploratory process with inferential intent. This process is presented both as a technique and as a research tool. The underlying assumption is that we can learn, gain new insights and increase understanding of a phenomenon, which in turn can inform practice. Building on this, Graneheim and Lundman¹¹⁹ have outlined the steps of content analysis in a pragmatic manner, starting by defining key concepts. Some of these concepts are: manifest and latent content, meaning unit, condensing, abstracting or interpreting, sub-theme and theme. Manifest and latent pertain to the level of analysis, looking at what seems obvious to the eye, reading the text, or trying to understand underlying issues. Both levels deal with interpretation, but the depth and level of abstraction vary. Meaning unit is the section of text (for example from a transcribed interview) that is scrutinized. Condensing is the next step in the analysis, where one aims to stay close and true to the original. Abstracting means interpretation of the underlying meaning. The final steps are the creation or naming of sub-themes and themes. Code is the label of the meaning unit, while category is a group of codes sharing commonality. Theme here is the underlying theme throughout the meaning units, condensation, interpretation and codes.

Content analysis can be used in many different ways and the different interpretations may confuse researchers and research consumers.¹¹⁷ Content analysis in this project has been used as an inductive method, moving from observation to broader generalization trying to detect patterns,¹¹⁸ and initially refraining from explicit interpretation in the condensation, aiming to stay true to the research process. Initial immersion in the material is common in qualitative content analysis, as described by Malterud.⁹⁵

Analyses in study II started by reading the transcribed interviews repeatedly, first without a particular aim but later with the study aim firmly in mind. Sentences, or meaning units, relevant to the aim were then digitally colored, cut and pasted into a separate Word document. When all the meaning units from one interview had been placed in one file, condensation of meaning units began, staying close to the original. All the meaning units were condensed before moving on to the next step. Interpretation

was the next step, trying to capture the underlying meaning and intent of the words. Sub-themes, and then finally themes, were suggested for the interpreted meaning. The codes and sub-themes emerged from the material and were not pre-existing categories. This process was performed with all fifteen interviews, one by one, using a vertical perspective. For examples of analysis, see Table 6.

Table 6. Example of an analysis matrix from study II.

Meaning unit	Condensation	Interpretation	Sub-theme	Theme
<i>"I believe it is important to have one leader for all, because leading is a big issue. But the important part kind of is..., it is not a flat line process, it is a hierarchical decision-making process... It is based on material that benefits from input by several people and how you work in the team".</i>	I believe it is important to have one team leader since leadership is crucial. The decision-making process is hierarchical and benefits from being based on impressions from several team members.	The team is well served by having one leader and a hierarchical decision-making process based on input from team members.	Leadership	Organisation
<i>"well... we all have issues, tragic events that we were a part of and that keep building up all the time, eventually you've had it! You might need to talk about it... We're all different, maybe not all..., but... maybe you get stuck on things, going over it in your mind. Could I have done something differently? and maybe you want confirmation and stuff like that..."</i>	You have issues and tragic events that keep building up inside, eventually you cannot deal with it. You might need to talk about it. We are different, but maybe we need confirmation.	One needs confirmation and support in knowing that the right thing was done in challenging situations. If not, then one might not last in palliative care.	Support group	Communication
<i>"Needs change so fast, so you do an important assessment and come up with a result and then you start over again. That's why I build on experience instead and that may be a problem since it makes it more difficult... Because what I think in my head is</i>	Needs change so fast that as soon as you make an investigation, you'll need to start over. You'll have to build on experience instead. It is more difficult because others cannot see the process in my head.	Needs change fast in this group. I base a lot on previous experience and others do not see the process in my head. My work is underestimated.	Approach	Competence

<i>not visible to others. It is difficult for others to understand that I actually perform this process in my head, that my conclusion of using this tool is only one of our options for interventions..."</i>	This tool is only one of our options.			
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When preliminary analyses of all interviews were completed, a brain storming session took place, two persons from the research group and me. Preliminary themes and sub-themes were presented and discussed in order to strengthen the analysis. Alternate themes or discrepancies were reflected upon. The research group then gathered and performed individual coding of approximately 10 percent of the meaning units. These meaning units were randomly selected, while at the same time ensuring that meaning units from each of the interviews were selected. Each member of the research group received the meaning units and deductively sorted them into the three themes provided. The aim was to strengthen credibility and to promote analytical rigor.^{95, 120} After the meaning units were sorted, comparisons were made and discussions ensued until negotiated consensus was reached.¹⁰²

The next step consisted of returning to the material to try and re-capture a sense of the whole. Each interpretation was re-evaluated and compared to the original meaning unit. Sometimes similar words had been used in the analysis of individual interviews and, aiming for congruence; choices were made as to the use of words. For example, the words ‘coordination’ and ‘collaboration’ had been used in a seemingly interchangeable manner during initial analysis, but coordination was then chosen for the theme *organization* while collaboration was chosen as a sub-theme in the theme *competence*. After all the data were sorted into different sub-themes and themes, each grouping was read through several times and a summary was verbalized and documented, in a horizontal analysis including all interviews.

4.5.3.2 Critical Incident Technique Analysis and Thematic Analysis

For study III, the transcribed individual interviews were read and re-read for immersion. Critical incidents, hereafter called care episodes, relevant to the aim, were digitally colored and inserted into a matrix, first in a vertical manner and then horizontally through the data. Every care episode was analyzed for words used to describe HCPs,

followed by inductive coding of the care episodes, extracting excerpts describing and evaluating care episodes and HCPs. The inductive coding¹¹⁷ was performed by firstly highlighting exact words from text that seemed to capture key thoughts or concepts, and secondly making notes of impressions and thoughts which resulted in codes. The codes were clustered together into categories depending on how they were linked or related. These preliminary results (categories) of the inductive coding were presented to an expert review group (n=6), in accordance with CIT methodology,¹¹⁵ aiming to strengthen the credibility and validity of the results. Based on their clinical and research experience within palliative care, this group discussed and reflected on (a) whether the results seemed reasonable, (b) if there were any surprising results and (c) if anything seemed to be missing. The discussion was regarded a part of the analysis process.

All care episodes were then deductively sorted into the categories from the initial inductive coding to see if they fit. Categories were adjusted to allow inclusion; for example, two categories were merged and the analyses continued by searching for potential themes evolving from the categories, and testing if these were appropriate and applicable for all narratives. Results from the deductive and inductive stances were continually compared, aligned and discussed. This process entailed shifting perspectives from inductive to deductive and back to inductive again multiple times in close collaboration and discussion with research group members. No new data was added at this point, since the purpose was to synthesize results and gain an overview of the results. Finally, the findings were translated into thematic sentences as described by Sandelowski and Leeman.¹¹⁴ The reason for translating findings into thematic sentences pertains to the accessibility and usability of qualitative findings. Thematic statements can convey findings and summarize key ideas while maintaining the complexity of the phenomenon, resulting in greater accessibility and usability for research consumers.

4.6 STUDY IV

4.6.1 Participants

Twelve SPHC teams in Sweden, representing a variety of team types (multiprofessional, interprofessional, transprofessional), meeting the inclusion criteria of practicing teamwork within SPHC and having different profession, were included. Patients (n=43), family members (n=45) and HCPs (n=61) from each team were included, see Table 7.

Table 7. Demographic data of participants in study IV.

	Patients (n=43)	Family members (n=45)	HCPs (n=61)
Median age (min-max)	67 years (34-87)	64 years (30-84)	50 years (27-65)
Gender			
Women	24	33	55
Men	19	12	6
Diagnosis			
Cancer	40	NA	NA
ALS	2		
NA	1		
Time since admission to team			Time in team
<1 week	1	1	<1 yr 5
1 week- 1 month	8	10	2-5 yrs 17
2 months-1 year	26	24	5-10 yrs 17
> 1 year	7	7	>10 yrs 22
No answer	1	3	
Frequency	Home visits	Care responsibility	
Several per day	3	14	
Every day	4	8	NA
Several per week	5	6	
Once a week	19	2	
As needed	12	15	

NA= not applicable

4.6.2 Design and procedure

In Study IV an exploratory, cross-sectional design was used. An exploratory design was chosen, building on the results of study II and III, since there are knowledge gaps in the area of teams in SPHC^{56, 121} and an exploratory design may be used as a first step to generate research questions or hypotheses for further testing.¹²² The approach in this study was quantitative, looking for patterns in a larger sample and trying to find statistical generalization.⁹ Associations of known aspects of teamwork: team type,⁶¹ team maturity⁵⁷ and team effectiveness⁵⁷ were the foci of exploration and questionnaires were used to collect data. Data were collected in two steps, initially through a web survey addressing all palliative care teams from the Palliative Care Registry,⁴ and

secondly through postal questionnaires to patients and families currently admitted to SPHC and HCPs working in a SPHC team.

In the compilation and analysis of results, the ITEM model⁴⁷ was used since it provides greater possibilities for exploratory design. This model also provides a broader, more comprehensive map of dimensions of teams, crucial to understanding teams in health care research, see Figure 1.

4.6.2.1 The web survey

The web survey contained ten questions, four addressing demographic data and six comprising statements regarding team types, with acceptable internal consistency.⁶¹ The statements were derived from core themes on team functioning and used with permission from the original authors.¹²³

4.6.2.2 The questionnaires

The Edmonton Symptom Assessment System (ESAS) is a validated and reliable tool for assessing symptom burden.¹²⁴⁻¹²⁶ Since ESAS is used in palliative care contexts in Sweden¹²⁷ and is a tool recommended by the Swedish National Board of Health and Welfare,⁸ it was selected for use in this study in the revised version ESASr.¹²⁸ Ten symptoms, including pain, fatigue, nausea, breathlessness and well-being, are rated by patients and family members from 0 (the best) to 10 (the worst).

The FAMCARE-2 scale measures satisfaction with care in family caregivers and is a validated and reliable tool within cancer care.¹⁰⁰ Experiences are reported through 17 items, rating satisfaction with, for example, meetings, symptom management and palliative care team availability. FAMCARE has been assessed in an extensive systematic review and deemed both valid and reliable,⁷⁸ which merited its use in this study. Questions 2, 4-9 and 12 were identified as relevant to our aim and therefore included.

The purpose of the Group Development Questionnaire (GDQ) is to provide data on group developmental level, group effectiveness and perceived productivity through self-assessment.⁵⁷ The GDQ has 60 items where participants rate agreement or disagreement with given statements on a Likert scale. Examples of items in the GDQ can be found in Table 8. The Swedish language version, GDQ-SE3 was used.¹²⁹ The presence or

absence of characteristic behavior in various phases is detected through the responses to the questions.¹³⁰

Table 8. Sample items in the GDQ as reported by Wheelan & Hochberger (1996).

Group development	Sample items
Scale I	Members tend to go along with whatever the leader suggests.
	There is very little conflict expressed in the group.
	We haven't discussed our goals very much.
Scale II	People seem to have very different views about how things should be done in this group.
	Members challenge the leader's ideas.
	There is quite a bit of tension in the group at this time.
Scale III	The group is spending its time planning how it will get its work done.
	We can rely on each other. We work as a team.
	The group is able to form sub-groups, or sub-committees, to work on specific tasks.
Scale IV	The group gets, gives and uses feedback about its effectiveness and productivity.
	The group acts on its own decisions.
	This group encourages high performance and quality work.

4.6.2.3 *Data collection study IV*

In March 2013, a link to a web questionnaire was sent by e-mail to all palliative care teams registered in The Swedish Palliative Care Registry (n=121). Seventy-seven participants (team leaders⁹ completed the questionnaire online and forty-seven stated that they were willing to participate further in the study.

Based on the web survey, team leaders who had agreed to participate in further data collection were contacted via email and twelve SPHC teams in Sweden were strategically selected. In order to generate wider perspectives, the teams were chosen to ensure a variety of team types and a geographic spread as well as a mix of urban, suburban and rural areas.¹⁰⁹ Thirty envelopes with questionnaires were sent to the twelve teams. Each team received ten envelopes for patients, ten envelopes for family members and ten envelopes for health care professionals. Each envelope contained the questionnaires, information about the study and consent procedures, and the research group's contact information. In an attempt to reduce sampling bias,¹⁰⁹ team leaders were asked to recruit ten health professionals on duty the following working day. Each health

professional was in turn asked to recruit one patient and one family member, preferably those they were scheduled to visit next. The purpose was to introduce some measure of randomness and to reduce the burden on individual team members. One reminder to complete the questionnaires was sent by email to team leaders.

4.6.3 Analysis

4.6.3.1 Web survey and questionnaires

The dimensions of the web survey were treated as continuous variables and analyzed; the statements received one, two or three points depending on designation as described by Thylefors et al.⁶¹ The potential scores ranged from 6-18, where a low score (6-9) indicates multiprofessional functioning, a medium score (10-14) interprofessional functioning and a high score (15-18) transprofessional functioning.

Demographic data regarding participants were compiled and the questionnaire data from GDQ, ESASr and FAMCARE-2 were coded, entered into MS Excel files and analyzed using descriptive statistics such as min-max, median (md) and percent (%).

In the GDQ analysis, statements pertaining to the four different group phases were summarized and counted, providing raw data and a score for each individual.¹³¹ The individual scores for the four stages were averaged to obtain a mean group score for each stage and for each individual. The mean group scores on the different scales are utilized when determining the group development phase.¹³² The GDQ mean group scores in the different stages were compared to the norm for Swedish groups. The effectiveness ratio in the GDQ was calculated by dividing the teams' mean score on scale IV with the potential maximum score, and expressed as a percentage up to a possible 100%.⁵⁷ Mean effectiveness in GDQ phases II-IV was calculated. Productivity is a single item question asking participants to rate their productivity from 1-4; mean productivity was calculated for the teams in GDQ phases II-IV.

5 RESULTS

5.1.1 Results study I

One of the results of the translation and cultural adaptation proceedings was a Swedish version of the FAMCARE-2 questionnaire, which was ready for testing, see Appendix 2. In addition, the results include experiences and reflections on the research methodology used for translation and cultural adaptation of research instruments. Translating and culturally adapting research questionnaires is a complex, non-linear process, conceptually closer to interpretation than translation. To rely solely on back-translation is not sufficient for valid translation and cultural adaptation; reflection and discussion aimed at achieving negotiated consensus are crucial in order to strengthen the reliability and validity of the questionnaire in the new language.

Item CVI was generally found to range from 0.67 to 1.0.

Table 9. Relevance ratings on the 17 items in the FAMCARE-2 scale

FAMCARE-2 item	Expert 1	Expert 2	Experts 3, 4	Experts in agreement	Item CVI
1.The patient's comfort	X	X	X	3	1.00
2.The way in which the patient's condition and likely progress have been explained by the palliative care team	X	X	X	3	1.00
3.Information given about side effects of treatment	X	X	X	3	1.00
4.The way in which the palliative care team respects the patient's dignity	X	X	X	3	1.00
5.Meetings with the palliative care team to discuss the patient's condition and plan of care	X	X	X	3	1.00
6.Speed with which symptoms are treated	X	X	X	3	1.00
7.Palliative care team's attention to the patient's description of symptoms	X	X	-	2	.67
8.The way in which the patient's physical needs for comfort are met	X	X	-	2	.67
9.Availability of the palliative care	X	X	X	3	1.00

team to the family					
10.Emotional support provided to family members by the palliative care team	X	X	X	3	1.00
11.The practical assistance provided by the palliative care team (e.g, bathing, home care, respite)	-	X	-	1	.33
12.The doctor's attention to the patient's symptoms	X	X	-	2	.67
13.The way the family is included in treatment and care decisions	X	X	X	3	1.00
14.Information given about how to manage the patient's symptoms (eg., pain, constipation)	X	X	X	3	1.00
15.How effectively the palliative care team manages the patient's symptoms	X	X	X	3	1.00
16.The palliative care team's response to changes in the patient's care needs	X	X	X	3	1.00
17.Emotional support provided to the patient by the palliative care team	X	X	X	3	1.00
Proportion relevant	.90	1.00	.60	S-CVI (ave)	.90

X= regarded relevant for families, - = not relevant

Scale-CVI was found to be 0.90 and therefore initial content validity estimates indicate high validity.¹¹¹

5.1.2 Results studies II and III

The results of study II are presented in the themes *competence*, *organization* and *communication*. For an overview of sub-themes and themes, see Figure 3.

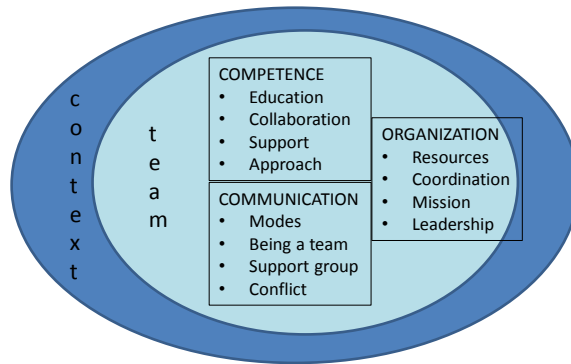


Figure 3. Themes and sub-themes presented in the results. Inspired by Kvarnström, 2008.

HCPs reported that work in a SPHC team is greatly impacted by allocated resources, the competence of individuals, organizational structures and leadership style. Team collaboration requires conscious effort and ‘being a team’ is demonstrated in communication patterns within the team as well as with patients and families. The team exists in a context that further impacts on HCPs’ experiences of working in a SPHC team.

The theme *organization* comprised reports of coordination in order to solve problems and optimize patient care. Participants expressed that leadership was critical since the formal leader creates a common understanding of what a team is and how this can be achieved. The theme *competence* pertained to education where participants stated that they did not have formal teamwork training. Further, the theme included descriptions of efficient teamwork and of creating an atmosphere that encourages collaboration. The final theme, *communication*, entailed descriptions of how the feeling of ‘being a team’ was created through communication, through supporting each other and through how conflicts were managed. With regards to conflicts, most HCPs stated that issues were discussed and resolved as a natural part of the working day.

For study III, the result of the thematic analysis regarding manifestations of teamwork in the care episodes is presented in the following two themes: ‘*Security: They are always available – I get the help I need quickly*’ and ‘*Continuity of care: They know me/us, our whole situation and they really care*’.

In total, 74 care episodes involving HCPs in SPHC teams were narrated by six patients and seven family members. Of the care episodes, 50 were descriptions of regular, scheduled visits while 24 related to acute care visits and/or interventions. Most care episodes narrated by the participants contained experiences of HCP(s) attending to the needs of the whole person, for example practical, medical, social and/or existential needs, even if the reason behind the contacts, especially in the acute care visits, was a physical or pharmacological need.

Critical incidents or care episodes were described in order to illustrate common every day SPHC team practices. The majority of the episodes described a physical need, but had repercussions for psychological issues such as experiences of feeling safe or cared for. The care episodes where participants described as having room for improvement had a common denominator, which was a need not being met; examples expressed by participants were forgetting an appointment, forgetting promised supplies or walking into a participant's house without being invited in. The last example was described as a violation of personal space and/or integrity.

The two themes represent patients' and families' narratives regarding manifestations of teamwork. The theme "*Security: They are always available – I get the help I need quickly*" contained descriptions of flexibility and sensitivity to changing conditions. Participants experienced feelings of security due to the availability of the SPHC team and that it did not matter who came, all HCPs seemed in agreement regarding care plans and interventions. This was true irrespective of whether it was during the weekend or on weekdays. The theme "*Continuity of care: They know me/us, our whole situation and they really care*" contained expressions by participants of being known and experiencing a continuous caring relationship. Information shared with one person was reported to the next and participants found this to be a positive example of collaboration. It also included experiences of care that encompassed more than symptom management. The way that the SPHC team works, in particular the attention to detail, resulted in the entire family experiencing continuity of care. This is an important component of the work of SPHC teams and is exemplified by the caring relationship between the HCPs and the family unit.

5.1.3 Results study IV

5.1.3.1 SPHC teams in Sweden – web survey

Out of 118 contact persons invited to participate, 77 (67%) completed the survey online. Registered nurses (49%), physicians (21%), team leaders (11%) and department heads (28%) were represented (more than one answer was possible). A majority had worked >10 years (52%) and others as follows: 6-10 years (18%), 1-5 years (25%) and <1 year (5%). The 77 teams had existed for: >10 years (33%), 6-10 years (30%), 1-5 years (28%) and < 1 year (9%). A majority (81%) of the respondents were female.

The most common responses to the questionnaire by team leaders (n=77) were found in the interprofessional (51%) and transprofessional (48%) areas of functioning, see Table 9.

Table 9. Specialized palliative care team functioning in Sweden regarding themes of functioning in relation to team types (n=77).

Themes of team functioning	Multi-professional functioning ^a	n (%)	Inter-professional functioning ^b	n (%)	Trans-professional functioning ^c	n (%)
Team Roles	<i>Team roles are specialized and everyone concentrates on his or her tasks</i>	3 (4)	<i>Roles are specialized but everyone is expected to interact</i>	41 (54)	<i>Although roles are specialized, everyone must also be prepared not only to complement, but to replace each other when necessary</i>	32 (42)
Team tasks	<i>Tasks are usually performed in a determined sequence</i>	6 (8)	<i>Tasks are partly interdependent and must be coordinated</i>	28 (37)	<i>Team members as well as their tasks are interdependent</i>	41 (55)
Coordination of activities	<i>Coordination is based on supervision or standardization</i>	1 (1)	<i>Everyone has to coordinate their activities</i>	38 (50)	<i>Coordination is achieved by direct close interaction, flexibility and improvisation</i>	37 (49)
Specialization of tasks	<i>Tasks are specialized and only those with a special professional education are allowed to perform the task</i>	9 (12)	<i>Everyone must be prepared to adjust to the task</i>	37 (48)	<i>Everyone must be prepared to adjust to the strengths and weaknesses of the others</i>	31 (40)
Team leader function	<i>The team leader functions as a traditional manager</i>	8 (11)	<i>The team leader functions as a 'coach'</i>	28 (37)	<i>The team leader varies with the situation; the team is self-regulated</i>	39 (52)
Theme for teams' work	<i>'Do your job in the best way you know'</i>	1 (1)	<i>'Do your job and cooperate'</i>	29 (38)	<i>'Do your job in an interactive way, and be ready for continuous improvements'</i>	47 (61)

^a 1 point per answer, ^b 2 points per answer, ^c 3 points per answer. Each team leader marked one statement per theme that best described their team functioning. Bold text represents the most frequent answers.

In the areas *team roles*, *coordination of activities* and *specialization of tasks*, the most common answers were found in interprofessional levels of functioning. For the areas *team tasks*, *team leader function* and *themes for teams' work*, the most common answers

were found in transprofessional levels of functioning. The distribution of web survey scores, implying team type, and number of teams per score are illustrated in Figure 4.

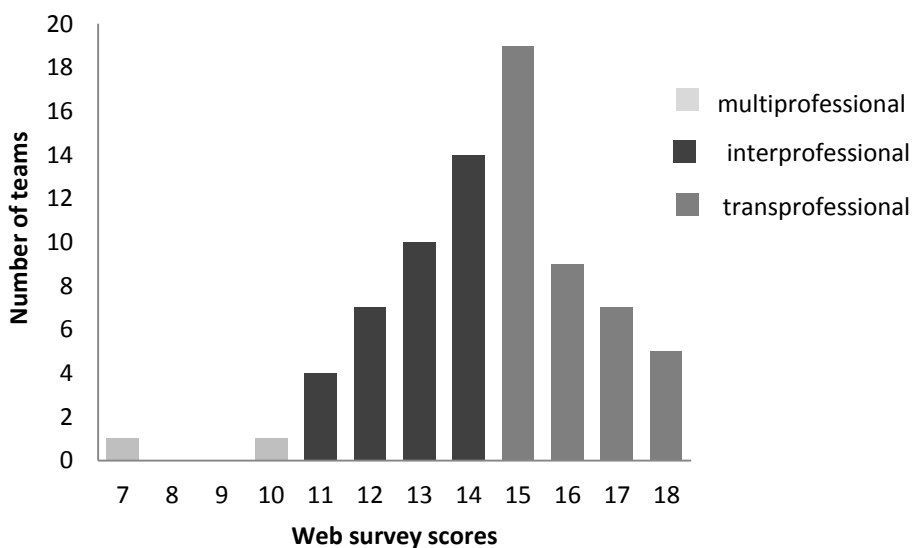


Figure 4. Number of teams and web survey scores. Chosen statements received one, two or three points based on description of team functioning.⁶¹ Scores ranged from 6-18: 6-9 indicates multiprofessional functioning; 10-14 interprofessional functioning; 15-18 transprofessional functioning.

5.1.3.2 *Group development questionnaire and group maturity*

The included teams have existed from between five and thirty years and all have a core of registered nurses, physicians and social workers. Physiotherapists and occupational therapists were present in a majority of the teams, while dietitians, assistant nurses, deacons and psychologists were mentioned by a few teams.

The GDQ questionnaire was completed by HCPs, excluding team leaders. All the teams included had been working together for at least five years in their present form. Teams were fairly evenly divided among phases, with four teams in phase II (counter-

dependency and fight), four teams in phase III (trust and structure) and three teams in phase IV (work and productivity). Team leaders of teams in phase II described teams as functioning mostly as interprofessional, and one was described as transprofessional. The effectiveness mean of the phase II teams was 64% (range 52-77), teams were located in rural, suburban and urban regions and the teams rated productivity with a mean of 2.95 (range 2-4). In the phase III teams, the effectiveness mean was 79% (range 76-80), teams were medium size, located in rural, suburban and urban areas and the teams rated productivity with a mean of 3.4 (range 3.1-4). In phase IV teams, the effectiveness mean was 83% (range 81-85), teams were located in rural areas and the teams rated productivity with a mean of 3.6 (range 3.1-4). Table 10 gives the results of the GDQ, including the web survey results.

Table 10. Health care professionals (n=61) ratings of team development in specialized palliative care teams (n=11) divided by GDQ phases of maturity (II-IV), including team characteristics, effectiveness and productivity.

GDQ phase	Team name ^a	Team start	Location ^b	Team size ^c	Team type ^d	GDQ score ^e	Effectiveness ^f %	Productivity ^g	Response %
II (n=19)	Alpha	2000	Suburb	M	Trans	15	52	4	54
	Bravo	1999	Suburb	L	Inter	12	62	3.5	
	Charlie	1998	Urban	S	Inter	14	77	2.3	
	Delta	2004	Rural	M	Inter	14	66	2	
III (n=26)	Echo	1999	Rural	M	Trans	18	76	4	64
	Foxtrot	1996	Suburb	M	Inter	11	80	3.3	
	Golf	1983	Urban	L	Inter	12	79	3.2	
	Hotel	2001	Rural	M	Trans	15	80	3.1	
IV (n=15)	India	1998	Rural	S	Trans	15	81	3.8	75
	Juliet	2008	Rural	S	Trans	18	86	4	
	Kilo	1995	Rural	L	Trans	15	82	3.1	

^a Fictive names for confidentiality. ^b Geographic context/location. ^c Team size: S=3-9 persons; M=10-19 persons; L=20-40 persons. ^d Team types as scored in the web survey; team leaders responses. ^e Scores ranged from 6-18: 6-9 indicates multiprofessional functioning; 10-14 interprofessional functioning; 15-18 transprofessional functioning. ^f Effectiveness of teams scored in the GDQ scale IV, included multiple dimensions of teamwork (structure, cohesion, organization, leadership, culture). ^g Productivity of teams, one-dimensional, self-rated from 1-4.

The group developmental phase, representing team maturity, was positively associated with the effectiveness rating. Effectiveness was calculated on multiple dimensions of teamwork such as structure, cohesion, organization, leadership, and culture.^{57, 58} Groups in phase II had lower effectiveness than groups in phases III or IV. The least effective group rated productivity highest (Table 3). The mean value of productivity as rated by teams in phase II was 2.95, in phase III 3.4, and in phase IV 3.63. Positive associations were found between team maturity and team effectiveness. Exploring associations between team type and team maturity showed that all mature teams (stage IV) were reported as transprofessional. Stage II teams had three interprofessional and one transprofessional teams.

The patients in this sample had advanced life-threatening conditions with multiple needs, common in specialized palliative care. Fatigue was the symptom the participants (n=38) scored highest, with all participants reporting some degree of tiredness, with a median score of 5 (min - max 1-9), while nausea received the lowest scores with a median score of 0 (min-max 0-7). Scores for other symptoms were: pain - median 2.5 (min-max 0-7); drowsiness - median 4 (min-max 0-9); lack of appetite - median 3 (min-max 0-9); shortness of breath - median 2.5 (min-max 0-9); depression - median 2 (min-max 0-9); and anxiety - median 1 (min-max 0-9). Most participants reported being affected by more than one symptom simultaneously: median 8 (min-max 4-10).

Family carers reported satisfaction with care through the FAMCARE-2 questionnaire; the results showed that 86% rated overall satisfaction at 86%. The lowest rating was found in meeting with the team, where 72% reported being satisfied with the meetings. The highest rating was 100% for satisfaction with team attention to symptom descriptions. These scores may serve as an indication that families are satisfied with the teams' attention to symptom description and would like better, possibly scheduled, meetings with the team.

6 DISCUSSION

The picture of SPHC teams in Sweden that emerges indicates that team members feel that they fulfil their purpose, which is of providing SPHC, and providing support for persons to maintain dignity, autonomy and a sense-of-self. The SPHC teams providing care in Sweden tend to work in interprofessional or transprofessional ways, and two thirds of the teams in this project were developmentally mature, having successfully negotiated the conflict phase. Patients and family members in turn report that they are satisfied with the care provided by a SPHC team and that it results in experiences of security and continuity of care. This was confirmed by the results in the translated and culturally adapted FAMCARE-2 questionnaire.

In the care episodes described by participants, the health care professionals are occasionally identified by their individual professions but most often they are referred to as a group. Nurses in particular were very rarely mentioned, instead personal pronouns (he, she, they) or the name of the service (ASIH, LAH) were used. An overwhelming majority of the care episodes in study III were managed by “unidentified” health care professionals, very likely nurses, who responded 24/7 to patient concerns. In SPHC, visits to patients and families are often performed by individual HCPs. How this relates to a “team approach”⁷ or an “interdisciplinary approach”⁶ is a pertinent question. In the 1990’s Tishelman¹³⁴ found that the nurse-patient relationship is not a one-to-one relationship, rather it can be better generalized as a relationship between an individual patient and a collective. Rasmussen and Edvardsson¹³⁵ found that, for hospice patients, the care and the environment are inseparable so that the “atmosphere of a place” is what contributes to or hinders patients’ experiences of well-being. In this thesis project, the entire team seems to be considered as a collective, or family as stated by patients, and together the SPHC teams promote an atmosphere of security and experiences of continuity of care. Research regarding expert teams has shown that they can develop a collective way of thinking, feeling and acting⁴⁸, which is confirmed by these results. Health care teams like this are adaptable and have the capacity to independently shift between being a task-oriented group to being a collective team.⁵⁴ How this relates to teams with variable HCPs⁴⁹ is unclear.

In contrast, several of the HCPs who participated in study II were concerned that other team members did not understand their profession or the work they do and most participants could not describe what the other professions did. This lack of knowledge is

in accord with national research,¹³³ which raises questions regarding how the SPHC teams seem to shift focus, depending on needs in patients and/or families, in a unified manner, which patients and families experience as a “collective” approach. It could be that HCPs are unable to explicitly state the specifics of other HCPs’ roles and responsibilities, but possess knowledge that is utilized instinctively or without conscious effort. In SPHC, not all HCPs visit the patient in the home, but instead referrals regarding patient needs are made based on input from the HCP who is in the home with the patient. Thus in effect, patients’ symptoms and needs are filtered through one team member before it reaches other team members. Reports from HCPs indicate different main foci with their interventions, for example maintaining dignity (physicians), strengthening self-image (occupational therapists) and “making it work at home” (nurses). In particular, physiotherapists and occupational therapists in this project expressed frustration at being the only person from their profession in the SPHC team and that patients were often referred to them too late, which, they emphasized, resulted in unnecessary suffering for patients and families. Teamwork is complex^{47, 53} and caring for dying persons and their families is similarly multifaceted⁴⁴ and clearly interprofessional teams do not guarantee multidimensional perspectives in patient care.¹³⁶ There are challenges that need to be addressed as described by participants in this thesis project. The definition of teamwork by Xyrichis and Ream⁵⁵ holds that teamwork requires two or more HCPs with complementary skills, common goals and who make a concerted effort. Furthermore, in order for teamwork to occur, there must be interdependent collaboration, open communication and shared decision-making, as stated by Xyrichis and Ream. How this is accomplished in the daily practice of health care services that offer a 24/7 service, operate a shift duty rota (staff choose their own schedules) and also struggle with ‘manning the stations’ is an interesting question. In effect, there are teams within the team (multiple microsystems),³⁸ depending on who is on duty. The nature of health care organizations does not seem favourable for teamwork in the strict sense of the word. If further variables such as hierarchies and territorial behaviour⁶⁸ among HCPs are added, the prerequisites for teamwork seem to be missing. For example, in the interviews with HCPs, participants reported their thoughts regarding what the team purpose was. These reports varied from person to person, even within the same team. These discrepancies can result in confusion regarding the purpose of the SPHC team and the services offered. Similar results have been described by Kvarnström¹³³ and reports from her study indicate that teams may lose holistic perspectives; this is especially serious since holistic caring is a cornerstone of palliative care.⁴⁶ In SPHC teams, physicians and nurses often comprise the majority of team

members, while physiotherapists, occupational therapists and social workers are present in smaller proportions. Dietitians, deacons, assistant nurses and psychologists were also occasionally represented in SPHC teams in this study. It has been stated multiple times that palliative care includes medical, ethical, psychological, social, existential and emotional dimensions.^{6, 7, 11} Presently team constitution does not seem to reflect this, since medical and nursing perspectives are dominant by force of numbers. Care dimensions may possibly be lost due to a lack of competence in certain areas.¹³⁷

The National Board of Health and Welfare in Sweden⁸ states that research cannot yet tell us which teamwork models are optimal for palliative care, yet teams comprising various HCPs continue to be recommended. In their review, Higginson and Evans⁵⁶ encourage research into ways of working as a team and whether a different mix of skills or team interventions are more effective for outcomes than others. Also, keeping cost-effectiveness in mind,^{76, 84} as well as assessing the needs for generalist or specialist palliative care,⁴⁶ trying the use of alternative models of care with physician-nurse groupings could perhaps be a start. Palliative care in Sweden has identified challenges with providing equitable care irrespective of region,¹³⁸ which is a stipulated right according to Swedish law. Developing physician-nurse groupings as a first instance, to initially assess and care for patients and families before full SPHC team involvement, may be a model to test. If the needs of patients and families become more complex, a referral to the full team could be made. Assuming that teams will function effectively and collaboratively without active effort is naïve,^{40, 43, 139} however, patients and families in study III reported that SPHC teams are successful in providing care that meets their needs. These results cannot be immediately generalized to larger populations, but patients and families in this study seem unaware of the SPHC team challenges and struggles. This presents an inconsistency; SPHC teams that lack HCPs in certain areas may lose holistic perspectives, yet generalist palliative care may be perfectly appropriate for some patients and families. This calls for an emphasis on assessing needs, having several options of palliative care delivery available to choose from as well as designing and allocating individually adapted palliative care depending on this assessment.

A lack of time for collaboration was emphasized by several HCPs in study II. Investigating time and team collaboration, Thylefors⁶² found that teams allocated approximately 10% of their working time to internal team meetings and evidence suggests that this is not a reliable predictor of team interdependence. Rather, team climate and team organization are key factors for team “tightness” or interdependence. Therefore providing more time is not the sole redeemer if team climate is more

important to team performance, even though collaboration does require time to reflect on vision and process.⁵³ It is possible that some of the effective and productive teams participating in the studies in this thesis have a culture conducive to collaboration⁴⁸ and therefore members underestimate the time invested in planning or do not regard it as an issue.⁶² Having a culture conducive to teamwork is presented by King and Harden (in Salas and Frush)⁴⁸ as crucial for sustaining teamwork, describing a need for teamwork behaviours to be embedded in the culture. In order to promote a culture of teamwork, they suggest training in teamwork communication skills for all HCPs as a first measure, with periodic refresher courses. That system-based communications training improve clinician performance is supported by findings from a systematic review of communication at the end-of-life.¹⁴⁰ Very few of the HCPs in this thesis project reported having had any teamwork or communication skills training at all and this may be one explanation for the diverse responses with regards to team purpose. If the team goes through training together, odds increase that team goals are explicitly stated. When team goals are not explicitly stated, then each HCP may interpret and state goals individually.

Teamwork can be executed in different ways and delineated models include descriptions of roles, coordination and leadership within multi-, inter- and transprofessional teams,⁶¹ developmental perspectives⁵⁸ closely related to effectiveness and productivity, individual HCPs knowledge, skills and attitudes⁴⁸ and other dimensions of teamwork (task design, organizational factors), as outlined in the ITEM framework.⁴⁷ Our findings indicate a correlation between group phase and team effectiveness. Perhaps this can be explained by what occupies the teams' time. In phase II, teams are busy testing boundaries, creating norms and structure as well as forming roles.⁵⁸ These are necessary steps for any team to move into a more effective and productive work phase. In our results, several teams were stage II groups, even though they had existed for several years. Usually, a team should move beyond conflict and opposition within six months.⁵⁷ There may also be individuals that lack the required knowledge, skills and attitudes for teamwork⁴⁰ or lack interest for participating in teamwork. It is unlikely that teams in development phase II function at an optimal level and it is possible that patients' and families' needs are not met to the extent they could be, even though patients and families themselves report being satisfied. One may also question the ability to provide high quality palliative care when framed by conflict and opposition. A large proportion of group energy goes into inter-team processes, instead of into the care of patients and families. Another issue is leadership, and if, for example, it is not in line with an interprofessional model, this creates a barrier for team members.^{61, 67} Teamwork is

complex, dynamic and adaptive⁸⁸, or it can be, given the circumstances. Focused efforts on role clarification, teamwork training, appropriate leadership style and developing interprofessional competence, like communication skills, would increase the odds for effective teamwork and would foster high quality palliative care.

6.1 METHODOLOGICAL CONSIDERATIONS

One purpose of methodological considerations is to consider the trustworthiness of the thesis. In this case, the translation and cultural adaptation of a research questionnaire (I), the two interview studies (II, III) and the exploratory questionnaire study (IV). This is presented as a discussion in narrative form below.

Performing high quality research in palliative care is difficult^{82, 86, 141} and some of the barriers that have been identified are funding, institutional capacity, researcher workforce, gatekeeping and misunderstandings related to palliative care in both public and professional arenas. In palliative care settings, it is crucial that the research questions are assessed for relevance and potential generation of knowledge as well as potential clinical application, before researchers take up some of this limited time.⁸¹ During the course of this thesis project we have sincerely strived to generate and keep to important research questions. This has been through exploring and describing SPHC team interactions (II) as well as patients' and families' experiences of SPHC teams' work (III), thus adding to evidence by confirming and consolidating earlier qualitative research findings.⁹ Also by translating and culturally adapting a research questionnaire (I) and using it in a quantitative approach with validated questionnaires (IV) to generate findings with larger potential for statistical generalization.¹⁰⁹ Since teamwork is a suggested standard for palliative care delivery, and since team performance and team effectiveness are reported to impact on patients' and families' well-being and symptom burden, appropriate and important research questions have been given full priority. Aiming for a wider base for transferability and/or generalizability, we have used strategic quota selection of participants, for example including teams (II), patients and families (III) from different geographic locations and in urban, sub-urban and rural areas. This strategy is in line with the aim and rationale of the thesis. In Sweden it is a challenge reaching patients and families in SPHC since guidelines and patient integrity laws dictate contact through the health care providers, often team leaders. The selection of patients and families in all the studies (II, IV) was done by the team leaders or HCPs. Aiming to introduce some measure of randomness; we suggested approaching all patients receiving palliative care team home visits on a certain day. Whether team

leaders adhered to our suggestion is however unclear. It is possible that the selection was biased by the choices made by team leaders. Gatekeeping is a known phenomenon in palliative care⁸¹ and reasons for gatekeeping include fear of burdening the patient, difficulties with disclosing patients' health status and doubts of the importance or quality of the study.¹⁴¹ Since the participants were severely ill, or had a severely ill family member, yet expressed a wish to participate, it is our belief that the sample comprised participants common in SPHC and therefore the findings may be transferable to other SPHC settings.

In study II, it is likely that the participants' long experience of working in specialized palliative care teams affects the result, one could even assume that they are comfortable working in palliative care and generally have positive impressions regarding their work. Choosing the date for the interview and asking to be able to interview a person on duty that specific day was an attempt at reducing this effect. The persons interviewed seemed representative for HCPs working in palliative care in Sweden with low turn-over rates and high dedication to patients and families.

The interviews (II, III) were conducted with the aim of understanding the participants' experiences and thoughts on the interview topics.¹⁴² In qualitative interviewing it is important to be aware of one's preconceptions and to reflect on them as part of the process.⁹⁴ Having worked in SPHC for several years means that I have knowledge, experience and opinions regarding most things within SPHC, from a nurse's point of view. These may be in accord with participant experiences, or in conflict with them. I have strived to be aware of such preconceptions⁹⁵ during the research process; they can help in formulating research questions and interpreting results or they can hinder if they bar the way to alternative questions or interpretations. Two persons in the research group were from outside the palliative care context and so research group reflections were utilized as a tool to challenge inherent assumptions. The persons from palliative care contexts had extensive clinical and research experience. The lively academic and abstract-concrete debates provided the foundation for research analyses and conclusions. Interviews may be especially suitable when one wants to study persons' experiences or views of meaning in their lives, describing perceptions and perhaps clarifying and developing their perspectives.^{94, 95} The intention was that the interview would be perceived as a natural conversation, not an interrogation, even though the interviewer guided the conversation and prompted with questions.¹⁴³ Occasionally participants wanted to discuss a topic not included in the interview guide. The interviewer allowed

this to happen for some time and then steered the conversation back towards the aim of the study. In some interviews with severely ill patients (III), an almost physical awareness of the limited time they had left in life served as a poignant reminder of the importance of not wasting time with irrelevant questions. This sometimes presented a challenge for me as an interviewer and required focus, re-iterating consent or asking if they really wanted to go through with the interviews. All the patients in this sample emphasized that they wanted to help others who would be in the same situation in the future. They expressed how participating in the interviews gave a purpose to that day and a sense of contributing to something for the benefit of others. Writing field notes and debriefing with other members of the research group were strategies employed in order to maintain research focus and a stance as a “professional” researcher (in training).

In both study II and study III, a semi-structured interview format was used and the dynamics were allowed to vary depending on participant preferences, nevertheless we found that the answers were congruent to a large extent. This may indicate that the results obtained from different geographic locations may be transferable to other similar health care settings. The results in study II reflect experiences of teamwork in palliative care for six patients and seven family members in five locations in Sweden; the results must be weighted accordingly. Demographics indicate that all but one of these persons was married and in a long-term relationship. It is possible that persons living alone have other experiences. Persons who have migrated to Sweden may also have other experiences of SPHC. In future studies, care should be made to reach out to a more diverse population with an element of randomization.

Patients’ and family members’ participation rate (III, IV) could be considered as low. This is possibly an effect of having to deal with life-threatening illness and approaching death.¹² It seems reasonable since several patients started the interview by stating that they had not thought that they would die. This was not the focus of the study, neither was it in any of the questions. In these moments, the interviewer strived to acknowledge the presence of death in life and the interview proceeded. The attrition rate (IV) was higher than anticipated due to missing data, 42% of the participants did not turn the page in the FAMCARE-2 questionnaire. This small sample in study IV nonetheless represents a wide selection due to the fact that 11 teams, of different sizes, in different geographic locations and with different organizational structures, with team leaders (n=77), patients (n=43), family members (n=45) and HCPs (n=63) were included. Our combination of

interview (II, III) and questionnaire data (IV) in this thesis project can be considered yielding rich data and presents a broader description of the arena of SPHC teams.

Comparing data like symptom burden (IV) as assessed by different persons present a challenge since we did not control which patients were assessed and representativeness, an aspect of external validity, may be biased.¹⁴⁴ It is possible that in distributing questionnaires, HCPs avoided recruiting the most heavily affected by progressing illness (gatekeeping), while when HCPs themselves rated patients; they may have chosen the heavily affected patients. The illness trajectory was not taken into consideration. Selection of participants is one aspect with bearing on the internal validity.¹⁴⁴ In our case, aiming to avoid selection bias we encouraged team leaders and HCPs to include persons receiving home care visits on a certain day. We do not have knowledge of whether these suggestions were adopted. The data does, however, give an indication of the state and conditions of patients receiving specialized palliative care, as persons facing life-threatening illness with a median of 8 symptoms (IV).

Patients and family members (III) were interviewed while admitted to a team and in a position of being dependent on care. Perhaps results would differ if family were allowed time for reflection after the death of the ill person and then share their experiences after some time has passed.

In study IV, team leaders reported team function through the web survey. It is possible that the internal validity is challenged by ideals about how the team ought to work, if team leaders filled questions out with that in mind. There was a less than 70% response rate to the GDQ by some teams and the recommendations are that such teams should be excluded from the results. However, we elected to report these since, as far as we are aware, this was the first attempt at measuring SPHC teams using the GDQ in Sweden. This must be therefore taken into consideration when making inferences from the results.

7 SUMMARY AND CONCLUSIONS

The emerging picture of palliative care teams in Sweden reveals teams that have existed at least 7- 21 years, often are of medium size (10-19 persons) and work in either inter- or transprofessional ways, i.e. HCPs need and depend on each other in their work. This indicates that leadership in these teams is either in the form of coaching or the team is self-regulating, so the person leading the team shifts from one to another, depending on situation and needs. Communication patterns in SPHC teams contribute to feelings of “being a team”. Team climate is affected by HCPs’ knowledge and trust of competence in colleagues. The proportions of HCPs with different professions have an impact of the foci and delivery of care. In measuring outcomes of care, using validated questionnaires is recommended. In translating and culturally adapting questionnaires to new languages, using the decentering stance in combination with negotiated consensus and structured reflection seems promising for increased measurement validity.

For the 11 SPHC teams in this thesis, the group developmental phase, representing team maturity, was positively associated with the effectiveness ratio, indicating that effectiveness increases with maturity. All teams had physicians, registered nurses, social workers and physiotherapists, full- or part-time. Occupational therapists were included in 8 of 11 teams. A majority of the 11 SPHC teams in the study are both effective and productive; however the four teams in conflict phase II have an effectiveness mean of 64%, while mature teams in phase IV have 83%. All mature teams were reported as functioning as transprofessional and were located in rural areas. Patients cared for by these teams have serious, life-threatening illness with multiple symptoms and their families are satisfied with the care.

Patients and families cared for by SPHC teams experience security and continuity of care through the collective team approach with 24/7 availability as well as sensitivity and flexibility in meeting patients’ and families’ needs. Also through individual HCPs knowing the patient and family, caring for the “little things in life” and including the entire family unit in the care. This collective approach, or team atmosphere, contributed to patients and families experiencing a continuous caring relationship even though home care visits were performed by various HCPs.

7.1 CLINICAL IMPLICATIONS

Based on findings of the current project, the following is proposed to optimize effective teamwork in palliative care, including patient and family perspectives.

Focus on creating effective teams. Teamwork training including clarification of team goals and professional roles, as well as developing psychosocial traits (team cohesion) and structured team processes (including communication), should be prioritized by managers of SPHC teams.

Target areas that promote patients' and family members' experiences of security and continuity of care. These are the 24/7 availability of the SPHC team, practicing sensitivity and flexibility in meeting patients' and families' needs (including practical adjustments to enable care at home), fostering a collective team approach and relationship (individual team members know patients and families), including their whole situation, and demonstrating caring about the little things in life and the family unit.

Build teamwork skills and individualized, continuing professional development. Communication and communication patterns within the team create the feeling of being a team, and team climate as well as team performance is significantly impacted by knowledge of competence in colleagues with other professions. Interprofessional education giving clarity of own professional role and knowledge of other professions would most likely benefit patients and families.

Consider proportions of HCPs in SPHC teams. Team constitution and proportions of HCPs have an impact on the focus of care. In order to sincerely address multiple dimensions in persons within palliative care, assessment of needs (physical, psychosocial, existential) requires balanced proportions of HCPs in SPHC teams. All patients and families mentioned practical adjustments in the home, perhaps occupational therapists should be standard in all teams.

Using research questionnaires in health care, a stringent and structured method for translation and cultural adaptation is imperative for appropriate use of interpretation and judgment while maintaining research integrity. Translation and cultural adaptation is complex and should be given full priority.

7.2 FUTURE RESEARCH

Palliative care delivery for a SPHC team in conflict (phase II) must be challenging, which makes these groups especially suited for an intervention targeting effective teamwork, focusing on HCPs roles and team goals. Furthermore, how SPHC teams and SPHC team members are evaluated and how interventions to meet the result of these evaluations are constructed, would be of broad interest. Also, among the most effective groups in our material, there are both large and small groups. Interestingly, all the most effective teams were located in rural areas. More detailed studies regarding associations with more refined tools and analyses would be appropriate. Patients in this project mainly had cancer diagnoses, would patients with different diagnoses place different demands on palliative care? What will be the challenges for SPHC teams in the future?

Several studies of patients' and families' experiences of palliative care in the home have been performed. A meta-analysis of these would be interesting to provide a broader evidence-base and perhaps more generalizable findings. Similarly, a meta-analysis of HCPs experiences of working in SPHC or perhaps palliative care teams in general would be appropriate.

It is still unclear which components are most crucial for effective SPHC teams. Could there be standardized models of team care? Perhaps comparing 'full' SPHC teams to nurse-physician groups where other HCPs act as consultants could be an interesting option? Persons in need of palliative care are increasing and specialized palliative care is not needed for all. Perhaps models of generalist palliative care can be explored in order to contribute to sustainable health care?

7.3 SVENSK SAMMANFATTNING

I Sverige dör omkring 89 000 personer varje år. Tidigare var det vanligt att personer dog på sjukhus, men det har förändrats så att omkring 50 % dör utanför sjukhus. Palliativ vård syftar till att lindra lidande och främja välbefinnande för personer med livshotande sjukdom och deras närstående, med fokus på helhetsperspektiv som inkluderar fysiska, psykosociala och andliga eller existentiella dimensioner. I Sverige har palliativ vård funnits omkring 40 år, även om det varierar i landet, och i en europeisk kartläggning anses den palliativa vården i Sverige vara på avancerad och väl utvecklad nivå. Personer som vårdas inom palliativ vård är svårt sjuka och har ofta en diagnos som innebär ett hot mot livet. Förutom de rent fysiska aspekterna med besvärande symtom innebär det ofta en känsla av existentiell ensamhet som innebär behov av stöd. Familjer inom palliativ vård har utmaningar eftersom de också står inför döden av en närstående samtidigt som de i hemmet ofta vårdar den sjuke och har behov att lära sig vårda samt behöver stöd i detta. Teamarbete är den rekommenderade modellen för organisation av palliativ vård, trots att nationella riktlinjer anger att vi ännu inte har kunskap om bästa sättet att organisera vård. Det kan göras distinktioner mellan ett team och en grupp, olika sätt att arbeta inom team och teams utveckling samt mognad. Alla dessa aspekter påverkar hur vården blir genomförd. Teamarbete ställer även krav på individer med avseende på kunskap, färdigheter och attityder så att om enskilda personer inte har intresse av att arbeta i team så påverkas teamet också av detta. Kvalitetsindikatorer inom palliativ vård syftar till att vara en standard för att kunna utveckla och utvärdera vård. Europeiska kvalitetsindikatorer för palliativ vård omfattar områden som: definitioner av palliativ vård, tillgång till vård, infrastruktur, instrument för utvärdering, hälso- och sjukvårdspersonal, dokumentation, kvalitet, patientsäkerhet, forskning och utbildning. Även här anges att gott samarbete i multiprofessionella team är viktigt för vårdens utfall. Mätning av vård och utfall av vård framhålls som viktiga i kvalitetsförbättring. Användandet av väl validerade instrument möjliggör detta. Det är inte rekommenderat att skapa nya frågeformulär om det finns väl validerade internationellt sett, utan översättning och kulturell anpassning bör då genomföras. Den inneboende komplexiteten på området med hälso- och sjukvårdsorganisation, olika modeller för teamarbete, personer med livshotande sjukdom och deras familjer utgör grunden för detta forskningsprojekt. Det finns kunskapsbrist kring hur organisation av vård i hemmet påverkar vårdens utförande och utfall för patienter och närstående. Hälso- och sjukvårdspersonal förväntas möta svårt sjuka personer och deras familjer utifrån uppkomna behov, i deras hem genom att organisera sig i team. Ytterligare forskning

behövs för att samla evidens kring patienters och familjers erfarenheter av specialiserade palliativa hemsjukvårdsteam för en god palliativ vård som möter olika behov på ett värdigt och respektfullt sätt.

Syftet med avhandlingen var att utforska team funktion inom specialiserad palliativ hemsjukvård, med hälso- och sjukvårdspersonal, patienter och familjer, för att få en djupare förståelse kring strukturer och förhållanden så teamarbete kan stärkas. Data samlades in med ett arbete kring översättning och kulturell anpassning av ett frågeformulär (I), intervjuer av hälso- och sjukvårdspersonal (II), intervjuer av patienter och familjemedlemmar (III) samt genom frågeformulär till hälso- och sjukvårdspersonal, patienter och familjer (IV). Totalt deltog 175 hälso- och sjukvårdspersonal (15 studie I, 15 studie II, 6 studie III, 138 studie IV), 48 patienter (5 studie III, 43 studie IV) och 53 familjemedlemmar (2 studie I, 6 studie III, 45 studie IV). I delstudie I genomfördes en översättning till svenska samt en kulturell anpassning av frågeformuläret FAMCARE-2. Syftet var att översätta och kulturellt anpassa FAMCARE-2 för användande i Sverige samt för sista delstudien. Processen innebar flera steg enligt rekommendationer i internationell litteratur. Vi använde oss även av ett decentrerat förhållningssätt som innebär att man skiftar perspektiv där originalet inte ses som måttstock, utan målet är ett välfungerade frågeformulär i svenskt kontext. Processen innebär översättning till svenska av tre grupperingar, reflektion kring dessa översättningar i forskargruppen för att enas om en version. Sedan blev formuläret tillbakaöversatt av tre nya grupperingar och forskargruppen diskuterade och reflekterade kring tillbakaöversättningen och om några problem eller tveksamheter framkommit. Därefter enades gruppen kring en preliminär version av frågeformuläret. I nästa steg fick två närstående fylla i formuläret och tänka högt kring frågorna, områden som förståelse och relevans resonerades kring. Vidare fick sex hälso- och sjukvårdspersonal inom palliativ vård granska den preliminära versionen och skatta huruvida frågorna är relevanta för närstående inom palliativ vård. Resultatet blev ett översatt, kulturellt anpassat och initialt testat frågeformulär, FAMCARE-2, för vidare validering och användande i svenska sammanhang. I delstudie II intervjuades hälso- och sjukvårdspersonal (n=15) inom specialiserad palliativ vård i Sverige. Syftet var att utforska teaminteraktioner bland hälso- och sjukvårdspersonal inom specialiserad palliativ hemsjukvård. Intervjuerna genomfördes individuellt på personernas arbetsplatser och analyserades med innehållsanalys. Resultaten presenterades inom tre teman: *kompetens* där deltagarna beskrev vikten av utbildning, hur man samarbetar tillsammans, om behovet av stöd när man arbetar inom palliativ vård samt

förhållningssätt gentemot varandra och patienter samt närstående. *Kommunikation* där deltagarna berättade hur de kommunicerar med varandra genom lappar och telefonsamtal, att i kommunikationen skapar man ett känsla av att vara ett team. Vidare hur handledning var ett verktyg för att hantera utmaningar och att konflikter löstes som en naturlig del av arbetsuppgifterna. I temat *organisation* rapporterade deltagarna att resurser påverkar deras arbete ibland genom styrning mot aktiviteter som betalar bättre, vikten av samverkan och gemensam värdegrund. Ledarskap togs upp och i vissa team har olika professioner olika ledare vilket beskrev påverka vården. I delstudie **III** intervjuades patienter (n=6) och närstående (n=7) inom specialiserad palliativ hemsjukvård. Syftet var att undersöka hur teamarbete yttrar sig i berättelser kring vårdepisoder hos patienter och närstående i specialiserad palliativ hemsjukvård. Intervjuerna genomfördes i patienter och närståendes hem och analyserades med kvalitativ tematisk metod. Resultaten presenterades inom två teman. Första temat *”Trygghet: De är alltid tillgängliga – jag får den hjälp jag behöver snabbt”* innehöll beskrivningar av flexibilitet och lyhördhet för förändringar. Deltagarna uppgav att de upplevde trygghet eftersom teamet var tillgängligt och att det inte spelade någon roll vem som kom, all personal var insatta i vårdplaner och insatser. Detta var sant vare sig det var vardag eller helg. Andra temat, *”Vårdkontinuitet: De känner oss, hela vår situation och de bryr sig verkligen om oss”* innehöll uttryck där deltagarna beskrev hur de var kända och upplevde en kontinuerlig vårdande, relation. Information delades med andra i teamet och deltagarna beskrev detta som goda exempel på samarbete. Här förekom även beskrivningar av vård som innebar mer än symtomhantering. Sättet som det specialiserade teamet arbetar på, speciellt med uppmärksamhet för små detaljer, resulterade i att hela familjen upplevde vårdkontinuitet. Delstudie **IV** genomfördes i två steg. I första steget svarade teamledare (n=77) för enheter inom palliativ vård på frågor kring teamens arbete. Här framkom att de flesta teamen arbetar integrerat och är beroende av varandra för att kunna genomföra sina arbetsuppgifter. I andra steget svarade hälso- och sjukvårdspersonal (n=61) på en enkät om grupputveckling, patienter (n=43) på en enkät om symtom och närstående (n=45) på en enkät om nöjdhet med vården. Resultaten visar att teamen i studien (n=11) består av sjuksköterskor, läkare och kuratorer. Fysioterapeuter, arbetsterapeuter och dietister fanns i flera av teamen. Alla team hade funnits i minst fem år och upp till 30 år. Angående teamutveckling så befann sig fyra team i fas två (konflikt), fyra team i fas tre (tillit/struktur) och tre i fas fyra (arbete). De mest effektiva teamen fanns i faser tre och fyra. De arbetade till övervägande del mycket integrerat med varandra och med ett ledarskap som kunde variera beroende på situationen. Effektivitet och gruppmognad tycks ha ett samband. De

mest effektiva teamen i denna studie befann sig utanför storstadsområden. Patienterna i dessa team verkar vara representativa för avancerad palliativ vård med ett flertal besvärande symtom (median 8). Närstående var nöjda med vården och kunde möjligtvis tänka sig fler planerade möten med teamet.

Denna avhandling team inom specialiserad palliativ hemsjukvård i Sverige team som har funnits 7-21 år, med 10-19 personer i teamet och där man arbetar integrerat med varandra, dvs. att man är beroende av varandra i arbete. Detta antyder att ledarskapet utförs antingen i form av coachande eller som själv-reglerande beroende på situation och behov. Sätten att kommunicera bidrar till att man känner sig som ett team. Teamklimat påverkas av kunskap kring kollegors kompetens och den tillit man har till varandra. Olika proportioner av hälso- och sjukvårdsprofessioner påverkar vårdens fokus och utfall. I mätande av vård och vårdresultat rekommenderas validerade frågeformulär. Översättning och kulturell anpassning är en process som inte bör underskattas. Patienter och närstående som vårdas av specialiserade palliativa hemsjukvårdsteam upplever trygghet och vårdkontinuitet genom teamens förhållningssätt med tillgänglighet dygnet runt, lyhördhet i bemötande av patienters och familjers skiftande behov. Även att hälso- och sjukvårdspersonal känner patienter och närstående samt bryr sig även om småsaker och inkluderar hela familjen i vården framhölls som viktigt. Detta förhållningssätt bidrog till att patienter och närstående upplevde en kontinuerlig, vårdande relation trots att olika personer besökte dem i hemmet.

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10 APPENDICES

Appendix 1

FAMCARE 2 for carers

Think about the palliative care that the patient receives and the ways in which the palliative care team may assist or communicate with families or carers who support the patient. Please answer the following questions indicating how satisfied you are with this care.

Tick the box that best matches your experience.

How satisfied are you with:	Very satisfied	Satisfied	Neither satisfied or dissatisfied	Dissatisfied	Very dissatisfied	Not relevant to my situation
The patient's comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way in which the patient's condition and likely progress have been explained by the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information given about side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way in which the palliative care team respects the patient's dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meetings with the palliative care team to discuss the patient's condition and plan of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speed with which symptoms are treated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care team's attention to the patient's description of symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way in which the patient's physical needs for comfort are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability of the palliative care team to the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support provided to family members by the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The practical assistance provided by the palliative care team (e.g, bathing, home care, respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The doctor's attention to the patient's symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way the family is included in treatment and care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information given about how to manage the patient's symptoms (eg., pain, constipation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How effectively the palliative care team manages the patient's symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The palliative care team's response to changes in the patient's care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional support provided to the patient by the palliative care team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 2

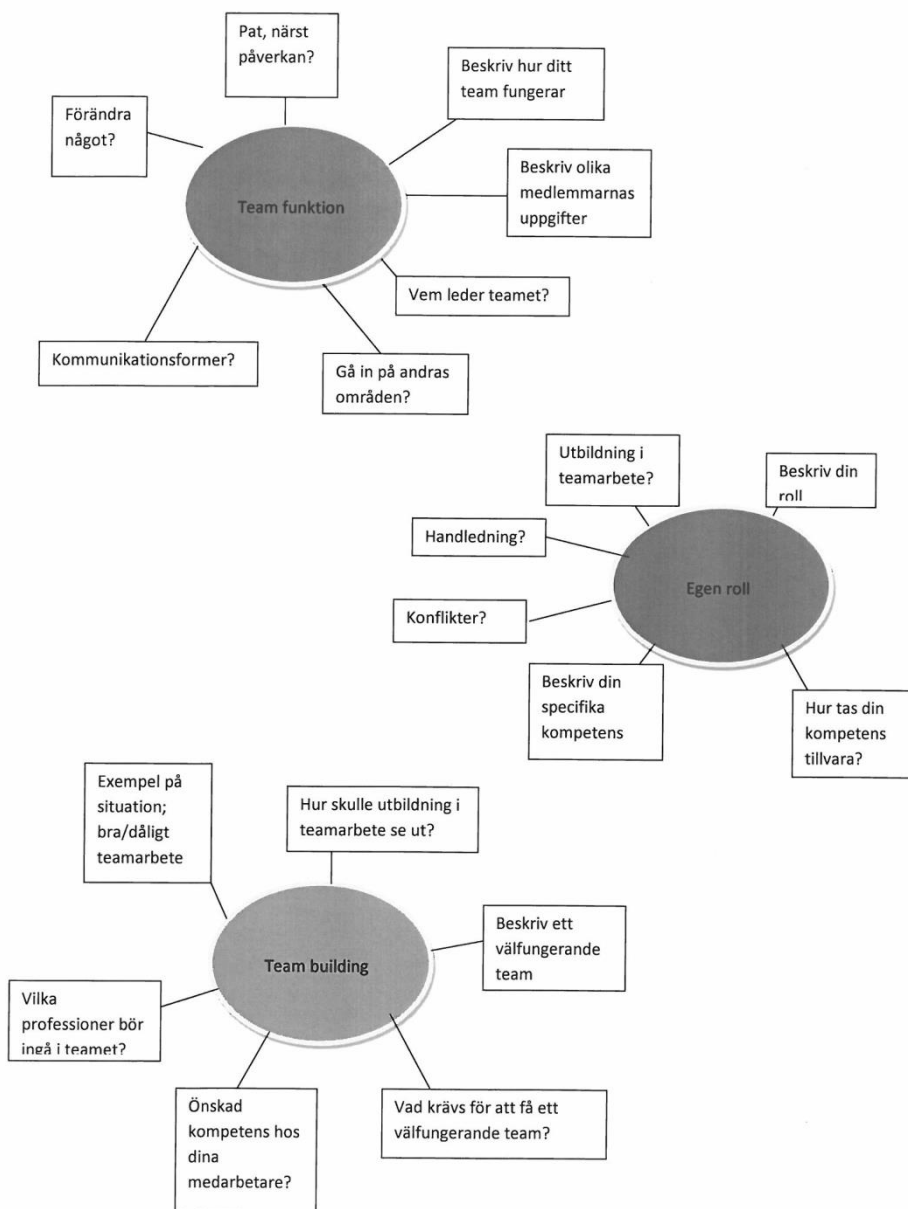
FAMCARE 2 för närstående

Tänk på den palliativa vård som din närstående får och på vilka sätt det palliativa teamet (namn.....) hjälper eller kommunicerar med dig som närstående. Var vänlig besvara följande frågor om hur nöjd du är med vården.

Sätt kryss i den ruta som bäst motsvarar din uppfattning.

Hur nöjd är du med:	Mycket nöjd	Nöjd	Varken nöjd eller missnöjd	Missnöjd	Mycket missnöjd	Inte relevant i min situation
Din närståendes välbefinnande	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det sätt din närståendes tillstånd och sjukdomens troliga förlopp har förklarats av det palliativa teamet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Den information som givits av teamet om behandlingsbiverkningar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det sätt som det palliativa teamet respekterar din närståendes värdighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Planerade möten med det palliativa teamet för att diskutera er närståendes tillstånd och planering av vården	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hur snabbt besvär/symtom behandlas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Den uppmärksamhet det palliativa teamet ger din närståendes beskrivning av sina besvär/symtom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det sätt på vilket din närståendes fysiska välbefinnande tillgodoses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tillgängligheten till det palliativa teamet för er närstående	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det känslomässigt stöd som ni närstående får av det palliativa teamet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det praktiska stöd det palliativa teamet ger, exempelvis dusch, toalettbesök, avlastning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hur läkaren uppmärksammar din närståendes besvär/symtom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det sätt ni som närstående görs delaktig i beslut om vård och behandling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Den information som givits om hur din närståendes besvär och symtom ska hanteras (t.ex. smärta, förstoppning)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hur väl det palliativa teamet hanterar din närståendes besvär/symtom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det palliativa teamets gensvar på förändringar av din närståendes vårdbehov	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det känslomässiga stöd som din närstående får av det palliativa teamet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 3



Interview guide – patient (English)

Thank you for taking time to share your opinions and experiences of being cared for at home. As a preparation for the interview, we would like for you to think about how it is to be cared for at home by several persons. Please think of specific examples that you can share with us. The examples may be of situations that have been to your satisfaction or situations that you would like to have been different. During the interview we would like to discuss your examples.

”We would like to know more about how it is to be cared for at home and we think you have valuable information that the health care services would benefit from knowing about.”

- Would you please tell me about the persons you meet in the care at home? Professions?
- What do you think it is like to be cared for at home by several different persons? Would you like to tell me more?
 - Do they work together? What are your impressions of their collaboration which each other?
- Would you tell me about a situation where something that happened regarding the care at home that seemed important to you or affected you in some way?
 - What happened?
 - What happened before that?
 - What happened after this?
 - Do you have other examples that you would like to share?
- Have you experienced any disagreements regarding the care at home?
 - What happened?
 - What happened before that?
 - What happened after this?
 - Do you have other examples that you would like to share?
- If you would write a wish list for the care at home, what would you wish for?

Interview guide patient (Swedish)

Tack för att du vill ta av din tid och dela med dig av dina synpunkter och upplevelser i att vårdas hemma. Som en förberedelse vill vi be dig tänka på hur det är att vårdas hemma av flera personer. Tänk gärna på konkreta exempel som du kan dela med dig av. Exempelen får gärna vara både om när det varit bra och när det varit mindre bra. Under intervjun kommer vi att prata om dessa tillsammans.

”Vi vill lära oss mer om hur det kan vara att vårdas i hemmet och vi tror att du har värdefull kunskap vården skulle behöva ta del av”.

- Kan du berätta vilka olika personer du träffar i vården hemma?
- Hur tycker du att det är att vårdas av flera olika personer hemma? Vill du berätta mer?
 - Jobbar de tillsammans? Samarbetar de väl?
- Kan du berätta om en situation där något som inträffat kring vården hemma spelat en viktig roll för dig eller påverkat dig starkt på något sätt?
 - Vad hände?
 - Vad hände innan?
 - Hur blev det sen?
- Har du fler exempel?
- Har du upplevt konflikter kring vården hemma?
 - Vad hände?
 - Vad hände innan?
 - Hur blev det sen?
- Om du fick skriva en önskelista för vården hemma, vad skulle du önska?